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**Early Intervention and Toilet Training:
Effects on Children with a Diagnosis of Autism Spectrum Disorder and their
Parents.**

By

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A thesis submitted in partial fulfilment for the requirements of the degree of
Doctor of Clinical Psychology

Coventry University School of Health and Social Sciences and University of
Warwick, Department of Psychology

May 2005

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LIST OF ABBREVIATIONS

| | |
|--------|---|
| ASD | Autism Spectrum Disorder |
| DSM-IV | Diagnostic and Statistical Manual of Mental Disorders |
| GAS | Global Achievement Scale |
| GP | General Practitioner |
| ICD-10 | International Classification of Mental and Behavioural Disorders |
| IQ | Intelligence Quotient |
| IPA | Interpretative Phenomenological Analysis |
| MMPI | Minnesota Multiphasic Personality Inventory |
| PDD | Pervasive Developmental Disorder |
| PECS | Picture Exchange Communication System |
| PSGQ | Parent Support Group Questionnaire |
| PSI | Parenting Stress Index |
| SPELL | Structure, Positive, Empathy, Low Arousal, Links approach |
| TEACCH | Treatment and Education of Autistic & Related Communication Handicapped Children |
| UK | United Kingdom |
| USA | United States of America |

ACKNOWLEDGMENTS

I would like to thank my academic supervisor, Dr Eve Knight, for her support, advice and containment of my anxieties throughout the research. I would also like to thank my clinical supervisor, Jacky Knibbs, for her enthusiasm, help accessing participants and advice. I would like to thank Dr Eve Fleming for her expertise and advice during the design and write up of the research, as well as Ms Val Redhead, for sharing her own experiences during the pilot stage. I am also indebted to Dr Delia Cushway for her support throughout the course as well as her enthusiasm and encouragement during the completion of my reflective paper.

I am thankful for the endless support that my colleagues within the IPA consultation group have provided throughout the analysis and writing up of the research. I thank them for their humour and for sharing their own research experiences with me; enriching this research.

I would especially like to thank all participants for sharing their experiences with me on a very sensitive topic.

I would like to thank my family and friends for letting me rant about the stresses of completing the research and for allowing me to spend less time with them. Especially my sister who has been planning her wedding without my being able to share her excitement. I would finally like to thank my boyfriend Steven for all of his wisdom, patience, kindness and ability to put things into perspective when I have lost myself within the research. He has kept me sane and well fed!

DECLARATION

This thesis was carried out under the supervision of Dr Eve Knight, Ms Jacky Knibbs and Dr Delia Cushway. Authorship of published papers will be shared with the above. Ideas for this research followed discussions with Dr Eve Knight, Ms Jacky Knibbs, Dr Eve Fleming and Dr Delia Cushway. A pilot interview for the Empirical Paper 1 was conducted and discussed with Ms Val Redhead. A consultation group was set up with colleagues also using the IPA methodology. These colleagues acted as independent auditors for the analysis of the interview transcripts for Empirical papers 1 and 2. Apart from the above collaborations, all of the material presented within this thesis is my own work. This thesis has not been submitted for a degree to any other university.

Ethical approval was obtained from Coventry University Research Ethics Committee and from the Local Research Ethics Committee (see Appendix A).

The thesis has been written for submission to the following journals (notes for contributors can be found in Appendix B):

Chapter I: Early Intervention for Autism Spectrum Disorder: Consideration of Parental Needs.

Journal of Autism and Developmental Disorders.

Chapter II: The Toilet Training Process: Experiences of Parents with Children
Diagnosed with Autism Spectrum Disorder.

Journal of Autism and Developmental Disorders.

Chapter III: Achieving Toileting Success: Personal Account of a Child with
Asperger's Syndrome.

Autism: The International Journal of Research and Practice.

Chapter IV: "Aqua wee (Accept Me)".

Dreaming.

SUMMARY

Current research has demonstrated that having a child who has been diagnosed with Autism Spectrum Disorder can have implications for the parents. Following a diagnosis of Autism Spectrum Disorder, early intervention has been utilised, being delivered either by professionals or the child's parents, both at home and in an educational setting. The aim of these interventions is to address the child's improvement in behaviour, socialisation and communication.

Only recently has literature started to focus on parents' needs and evaluating outcome for these parents when they are accessing different types of early intervention. A review of this literature reveals the need to develop systemic models considering child and parental needs and outcomes in early intervention. Before this may occur further research is needed to address the methodological limitations of the research reviewed in chapter I.

Whilst there is limited literature concerning difficulties with toilet training for children diagnosed with Autism Spectrum Disorder, there are clinical examples of difficulties with this task. In chapter II, eight interviews addressing toilet training were completed with parents of a child diagnosed with Autism Spectrum Disorder. A possible psychological conceptualisation of parent's experiences was developed. Limitations of the research and implications for clinical practice are considered

In chapter III, a single case interview addressing toilet training was completed with a child diagnosed with Autism Spectrum Disorder. A possible psychological conceptualisation of the child's experience was developed. Limitations of the research and implications for clinical practice are considered

In chapter IV the author presents a record of dreams that occurred throughout the research, accompanied by dream analyses. From these analyses lessons for the research were considered and converted into practice.

Overall word count for thesis: 17, 911

Chapter I

Early Intervention for Autism Spectrum Disorder: Consideration of Parental Needs

Chapter word count (Excluding tables, figures and references): 5576

ABSTRACT

There has been a wealth of research into the effectiveness of early intervention in addressing the needs of children with a diagnosis of Autism Spectrum Disorder. Research suggests that early intervention is effective in addressing developmental difficulties before the child enters formal education. Much of this literature has focused on parent led intervention programmes and why they do or do not work as effectively as clinician led intervention programmes. Although there has been some discussion of the parent's role within the implementation of these intervention programmes, there has been limited emphasis on the needs of parents and parental outcome following completion of an early intervention programme. The aim of this literature review is to critically review recent articles beginning to consider these parental variables.

INTRODUCTION

There has been an increase in awareness of Autism Spectrum Disorders (ASD) in the past few years, with clinicians usually being able to identify it before the child is 3 years old (Diggle, McConachie and Randle, 2002). This has led to an increase in referrals being made to services for diagnosis and support (Powell et al., 2000). However, after a child has been diagnosed, professionals may not fully appreciate the needs of children and parents (Shields, 2001).

The aim of early intervention is to bridge the gap between diagnosis and educational placement (Shields, 2001). Early intervention has previously been both child and parent focused. However, the outcome measures following early intervention that have been used to determine the efficacy and moderating factors in successful outcome, have been largely focused on child development, for example, variation in behavioural difficulties, level of social interaction and changes in sleep patterns.

AIMS OF REVIEW

The primary aim of this review is to focus on research specifically addressing the needs of parents participating in or administering early intervention packages.

This is an important area because parents may be involved in delivering these programmes to address the child's needs, however, until relatively recently, the needs of parents have not been fully considered.

The second aim of this review is to consider relevant outcome measures focusing on the needs of the parents and how early intervention may address these issues.

Following a summary of Autism Spectrum Disorder and the impact that having a child has diagnosed with this has on parents, early intervention will be introduced. The types of intervention frequently used to address the needs of children diagnosed with Autism Spectrum Disorder will be summarised. This will be followed by a critical review of the papers currently considering parental needs and measuring the outcome for parents participating in early intervention programmes. Finally, future directions for research will be considered based on the methodological limitations of the current research reviewed.

SEARCH STRATEGY

Papers were searched for using Psychinfo, Medline, and the Cochrane Reviews database. Search terms used within these databases were Autism, Asperger's Syndrome, Autism Spectrum Disorder and Pervasive Developmental Disorder. All of these diagnostic terms were cross referenced with the terms of Early Intervention, Behaviour Support, Parent Support Group, Parent Training, Educational Support and Developmental Support. After manually searching through articles that were found using the criteria, the diagnostic terms were again cross referenced with the terms found to be important in addressing parent needs and outcome. These terms were Stress, Mental Health, Depression, Anxiety, Coping and Parent Need. Identified journals were then searched for further references containing the latter search terms.

Only papers written in the past five years have been included in this review, although references contained within these papers from earlier years may be commented on. This is because the majority of historical literature in the field of early intervention has focused on child outcome measures. It has been a recent development to consider the impact of early intervention on parents. It is likely to be useful to develop an understanding of this area further, because parental factors, for example stress, may impact on the variability in child outcome measures.

Only papers specifically relating to ASD were used. Studies relating to children with additional disabilities or co-morbid developmental difficulties were excluded. Only empirical and review papers were included, because one of the main aims of this paper is to consider methodology and design issues, which theoretical papers may not address.

PREVALENCE OF AUTISM SPECTRUM DISORDER

ASD is the term used to cover the diagnostic terms of Autistic Disorder and Asperger's Disorder in the DSM-IV (American Psychiatric Association, 1994). ASD is a developmental condition, which includes difficulties with reciprocal social interaction, communication and imagination. There is no government central recording of prevalence, and epidemiological studies vary in their case finding methods and inclusion criteria. There is, however, consensus that there has been an increase in prevalence over the past thirty years (Fombonne, 1999; Taylor et al., 1999; Baird et al., 2000; Fombonne, Simmons, Ford, Meltzer &

Goodman, 2001). The National Autistic Society suggests that ASD affects an estimated 530,000 people in the UK. At least 1 in 400 children are affected by ASD (Diggle et al., 2002), with boys being four times more likely than girls to present with this (Wing, 1996).

In recent years, researchers have put forward a genetic explanation for gender differences in prevalence. Skuse (2000) has suggested that the gene/s for ASD are located on the X chromosome. Girls inherit X chromosomes from both parents and it is hypothesised that the X chromosome that girls inherit from their fathers contains a gene which "protects" from ASD, making girls less likely to develop it.

Family and twin studies demonstrate an increased rate of ASD amongst relatives, suggesting that genetic factors do play an important role in its causation (Folstein & Rutter 1977; Smalley, Asarnow & Spence, 1988; Bailey, LeCouteur, Gottesman & Bolton, 1995). However, it is a complex picture and does not appear likely to be due to a single gene.

A diagnosis of ASD may impact on children and their families in many ways, such as socially and educationally, which may then have psychological consequences (Wing, 1996). For this reason, early intervention has been introduced to support children and their families as soon as possible after a child has received a diagnosis of ASD.

Impact on parents when a child is diagnosed with Autism Spectrum

Disorder

The symptoms of ASD may impact on the interaction that the child has with members of their family, placing strain on parents (Sivberg, 2002). Studies have indicated that having a child diagnosed with ASD can be very stressful, due to the social, behavioural and cognitive aspects of the disorder that the child has (Koegel et al., 1992; Hastings & Johnson, 2001). It has been argued that stress and coping of mothers who have a child diagnosed with ASD are moderated by levels of challenging behaviours, support, social and economic situations within the family (Hastings & Johnson, 2001; Bromley, Hare, Davison & Emerson, 2004).

EARLY INTERVENTION

Types of early intervention

There are different types of early intervention for ASD regularly used in the UK. Some of these support parents in helping their child, such as the “EarlyBird” Programme, set up by the National Autistic Society (NAS) in 1997 (Shields, 2001). The aim of this approach is to help parents understand why the development and behaviour of their child may be different and how best to help their child.

The “Son Rise Programme” (Kaufman, 1998) is an approach that is interactive, emphasising the importance of developing a relationship and communication between the child and parents. The child becomes the teacher whilst the parent or instructor, therapist or facilitator, becomes the student. Like the “Early Bird” Programme, this approach is parent focused, with more potential to address parental needs whilst other early interventions programmes are more child specific.

Approaches focusing specifically on the child, are the “Structure, Positive, Empathy, Low arousal, Links” approach ([SPELL], Siddles Mills & Collins, 1997), “Treatment and Education of Autistic & Related Communication Handicapped Children” ([TEACCH], Schopler, 1994), and Picture Exchange Communication System ([PECS], Bondy and Frost, 1994). All of these approaches address communication, social skills difficulties and development of the learning environment and can be administered at home and in the classroom.

Behavioural approaches have also been widely used, such as the Lovaas/Applied Behavioural Analysis approach (Lovaas, 1987). This method aims to teach basic social, educational and daily life skills to children in the first five years of life, before they enter education.

Reviews on the efficacy of such early intervention programmes highlight many limitations with the research evaluating these programmes, suggesting an inability to provide families with information on the best practice (Freeman, 1997; Howlin, 1998; Jordan & Jones, 1999; Prizant & Rubin, 1999). There is,

however, a consensus regarding features of interventions that are deemed important, such as interventions being provided early, parents being involved, with a focus on developing joint attention, communication and social understanding in the child. It is further recommended that the child's strengths and interest be used in early intervention programmes and children should have access to typically developing children (Jordan & Jones, 1999; Prizant & Rubin, 1999).

Early intervention and parental need

Wolery and Garfinkle (2002) review factors that contribute to the variability in child outcome measures administered during early intervention programmes. They argue that systems theory is best used to identify moderating factors in child outcome following early intervention. They describe risk and opportunity factors for child outcome when engaging in any learning experience. Various variables relate to the characteristics and circumstances of parents themselves that may be useful to address and consider in early intervention, to increase child opportunities when engaging in learning. These factors are mental health, self-esteem, social skills, coping skills, quality of parent/child interaction and parenting style and support.

Although research regarding parental need and outcome is in its infancy and Wolery and Garfinkle (2002) argue that it is not clear how these factors moderate child outcome, further research will facilitate the development of appropriate theories. When searching the literature it was clear that there was limited

consideration of these factors. However, if as the research suggests, parental factors facilitate change in children, they need to be considered when administering as well as evaluating early intervention programmes. Before the interaction between such variables is considered, the needs of parents should be considered, as should the effectiveness of early intervention programmes in addressing these needs.

Schopler (1987) argued that parents are the most important resource in promoting the behaviours of a child with ASD. However, the needs of parents and outcomes following participation in early intervention have been neglected. These variables need investigating, in order to best support parents in providing this resource for their child. It has been argued that early intervention for children diagnosed with ASD should provide support for the family system and should aim to focus on the reciprocal relationships that exist between the child's behaviours and family interactions (Dunlap, 1999; Bromley et al., 2004). Before this can be achieved an understanding of parent needs should be considered. The articles reviewed that address this issue are summarised in table 1.

Table 1: Summary of articles covered in the literature review

| Author | Design | n | Age of children | Gender | Diagnosis | Parents | Intervention | Setting | Parent Measures | Outcome |
|-----------------------------|---|----|--------------------------------|----------------------|---|---------------------------|---|---------|--|---|
| PARENT NEEDS | | | | | | | | | | |
| Moes and Frea (2002) | Multiple Baseline | 3 | Between 3-5 years | 2x male 1x female | 2x Autism 1x High functioning Autism | Both parents | Behavioural - Functional Assessment and Functional Communication Training | Home | Interview Parent Support Survey | Assessment of family needs contributes to stability and durability of reductions in challenging behaviour |
| PARENT OUTCOME | | | | | | | | | | |
| Bitsika and Sharpley (1999) | Pre-post exploratory | 14 | Not known (parent's age given) | Not known | Autism | 13 x mother 1 x father | Group counselling and problem discussion training programme | School | Parent Support Group Questionnaire (PSGQ) AND Parent Evaluation Feedback Questionnaire | Slight positive changes in the factors measured in the PSGQ. Findings not consistent or generalisable. Parents felt support but not specific enough to address problematic manifestations of stress |
| Bitsika and Sharpley (2000) | Pre-post and Retrospective quantitative and exploratory | 11 | Not known (parent's age given) | Not known | Autism | Mothers | Parent support programme teaching behavioural stress management | School | Parent Support Group Questionnaire -- version 2 AND Programme Evaluation Questionnaire (PEQ) AND Self- | Positive ratings of programme. Biofeedback based stress management techniques most valuable part of programme. |

| Author | Design | n | Age of children | Gender | Diagnosis | Parents | Intervention | Setting | Parent Measures | Outcome |
|--|----------------------------------|----|--------------------------|-------------------------|----------------------------|---|--|-------------------|--|--|
| Chandler, Christie, Newson and Prevezer (2002) | Multiple Baseline | 10 | 1yr 10mths -- 2yrs 9mths | 9x male 1x female | Autism | Not stated | Address expressive and receptive communication and reciprocal play | Home | Rating Depression Scale AND Self rating Anxiety Scale Interview | No significant changes in stress, anxiety and depression. Reported being given a clear approach and strategies for managing child's behaviour. Developed understanding of autism and learnt how to engage their child. |
| Engwall and MacPherson (2003) | Pre, Post and follow-up | 24 | Mean = 50 months | 20 x male 4 x female | Autistic Spectrum Disorder | 12 x both parents 8 x mothers 1 x father 3 x mixture of parent, carer and grand-parent | "Early Bird" - Parent training | Not known | Parenting Stress index [PSI](short form) AND Early Bird Centre Post and Follow-up Programme Questionnaires AND pre and post Local Questionnaires | PSI scores significantly reduced post programme. Stable at 6 months follow-up. Reported confidence in managing child's behaviour. Enjoyed meeting others, sharing advice and decreased feelings of isolation. Had also altered communication style with child. |
| Koegel and Koegel (2002) | Non-concurrent Multiple Baseline | 5 | 3yrs10mths -- 5yrs 7mths | 2x male 3x female | ASD | 4x 2 parents 1x 1 parent | Parent Education | Clinic play-rooms | Parental Composite Affect Ratings (happiness, interest, stress) | Parents appeared happier, less stressed and more interested during interactions with child. |

| Author | Design | n | Age of children | Gender | Diagnosis | Parents | Intervention | Setting | Parent Measures | Outcome |
|---|--|----|--|--|---------------------------------------|--------------------------------|----------------------------|------------|---|---|
| Salt, Shemilt, Sellars, Boyd, Coulson and McCool (2002) | Two-group, pre-test, post-test | 20 | Mean = 42.36 months (treatment) Mean = 37.67 months (control) | Male: female = 11:1 (treatment) 3:2 (control) | Autism | Not known | Socio-developmental | Not known | Parenting Stress Index -- 3 rd edition (short form) | PSI scores decreased for treatment group and increased for control group but not significantly. |
| Smith, Buch and Gamby (2000) | Multiple baseline - Experimental | 6 | 35-45 months | 6x male | Autism or PDD not otherwise specified | 4x 2 parents 2x mother only | Lovaas – Behavioural | Home | Parenting Stress Index AND Parent Satisfaction Questionnaire | Parents reported normal levels of stress during and after treatment. High parent satisfaction but did not lead to long-term developmental gains. |
| Sofronoff and Farbotko (2002) | Two-group, pre-test, post-test and follow-up | 45 | 6-12 years | Not known | Asperger's | 44x 2 parents 1x 1 mother | Parent Management Training | University | 'Parental self-efficacy in the management of Asperger syndrome' questionnaire | Increased self-efficacy in mothers significantly more so than fathers in both treatment groups compared to the control group. |

PARENT NEEDS AND OUTCOME

| | | | | | | | | | | |
|---------------------------------------|-------------------|---|------------------|------|--------|--------------|---|---|---|--|
| Weiskop, Matthews and Richdale (2001) | Single Case Study | 1 | 5 years 4 months | Male | Autism | Both parents | Behavioural programme and parent training | Home x 2 sessions Clinic x 1 session | Goal Achievement Scale (GAS) AND Programme Evaluation Questionnaire | Results of the sleep programme were clinically significant and maintained at 3 & 12 month follow-up, based on GAS. Parent satisfaction was high. Mother's self- |
|---------------------------------------|-------------------|---|------------------|------|--------|--------------|---|---|---|--|

| Author | Design | n | Age of children | Gender | Diagnosis | Parents | Intervention | Setting | Parent Measures | Outcome |
|-----------------|-------------|----|-----------------|-----------|---|--------------|-------------------------------------|-----------|---|--|
| Whitaker (2002) | Exploratory | 16 | Under 5 years | Not known | 8 x Autistic Spectrum Disorder 4 x Asperger Syndrome 4 x Autism | Mothers only | Parent support (Early Bird Project) | Not known | Interview with open ended and rated questions | confidence increased with improvement in child's sleep. Support worker rated as very useful. Valued support provided to nurseries/schools the child attended, practical strategies and education that developed parents' understanding of their child's development and needs. |

The articles reviewed that address parental need and outcome following completion of an early intervention programme, have been completed in various countries. This needs to be considered when interpreting the findings from these papers. Of these papers, four were completed in Australia (Bitsika & Sharpley, 1999 and 2000; Weiskop, Matthews & Richdale, 2001; Sofronoff & Farbotko, 2002), three in the USA (Smith, Buch & Gamby, 2000; Koegel & Koegel, 2002; Moes & Frea, 2002), two in England (Chandler, Christie, Newson & Prevezer, 2002; Whitaker, 2002) and two in Scotland (Salt et al., 2002; Engwall & MacPherson, 2003). It is possible for example that different pressures and support for parents are provided in different countries, which may impact on levels of parental need.

Moes and Frea (2002) addressed the needs of three families who had children diagnosed with Autistic Disorder and who were displaying behavioural challenges that were disruptive to the family. They conducted a functional assessment and family interviews to determine care giving demands, family support and patterns of social interaction associated with daily routines. Family needs for support and patterns of desired interaction were explored. Intervention was administered in a teaching session and then contextualised in relation to when, where and with whom the behavioural challenges occurred.

All three families reported the need for both parents to share demands within the home and to provide mutual emotional support for each other by encouraging and giving positive feedback. Parents also reported the importance of spending time alone with each other as well as giving equal attention to siblings.

Demands reported by these families were addressed directly by changes being made to the administration of the intervention package. Impact of the intervention was measured by asking parents to complete the Support Plan Survey. This 20 item self-report questionnaire was based on an instrument that was designed to measure “contextual fit” of behavioural support plans. (Albin, Lucyshyn, Horner & Flannery, 1996). It contains questions regarding compatibility between intervention, parental resources, constraints, beliefs, values and goals. However, this measure was used to determine sustainability of intervention rather than “contextual fit” and how this was done was not detailed. This measure did not determine direct impact of intervention on parents themselves.

Of the articles reviewed, two further articles considered the needs of parents as well as measuring outcome based on identified need, varying in design and intervention administered (Wieskop, Matthews & Richdale, 2001; Whitaker, 2002).

Weiskop et al. (2001) used a single case design to determine the needs of a mother and father of a child with sleep problems. They used semi-structured interviews to determine the needs and goals of the parents for changing their child’s sleeping behaviour and utilised formal measures to evaluate the extent to which goals were met. These measures were the Goal Achievement Scale (Hudson, Wilken, Jauering & Radler, 1995) and the Programme Evaluation Questionnaire (Griffin & Hudson, 1978).

The Goal Achievement Scale requires parents to state the goals of treatment and rate achievement of them from 0 to 100%. Baseline rating always starting at 0% with success not necessarily meaning that the behaviour has entirely ceased. The Programme Evaluation Questionnaire consists of three open-ended questions about what the parent likes, dislikes and would change about the behavioural intervention. Remaining questions in this questionnaire are rated on a five point Likert scale for parent's approval of the techniques, improvement in child's sleep and behaviour, reduction in parental stress levels and how strongly parents would recommend the programme to a friend. Results from this study suggested that the mother's self-confidence improved as the child's sleeping improved, although no correlation was calculated to support this argument.

Whitaker (2002) provided a parent support group based on needs that were previously determined by asking parents of children diagnosed with ASD to complete postal questionnaires. Service developments were made and parents, who had accessed the service and had then been discharged, were asked to complete a semi-structured interview, which incorporated open-ended ratings of the service. This study appears to be the most exploratory piece of research completed recognising parents' needs and unmet needs around the time of diagnosis and provision of early intervention. The unmet need described most frequently by parents was the lack of information at the time of diagnosis. Parents reported that they required information about ASD in general as well as in relation to the individuality of their child.

Parents also suggested that there was a need for clarity concerning the meaning of the diagnosis. Although parents have access to lots of information with advances in technology, this can be overwhelming and it is important for parents to be given some guidance concerning the most relevant information that will suit them. In addition, consideration of the psychological needs of parents during the time of diagnosis, as well as the offer of mutual support and contact with other families going through similar circumstances, was reported as important.

Given the needs that have been identified from this group of parents, further exploration of the needs of parents generally when accessing early intervention support is warranted. Many of the early intervention strategies employed are based on addressing change in the child, but not the impact that having a child diagnosed with ASD has on the parents. This needs further exploration because of the impact that it could have on parental beliefs about self-efficacy (Hastings & Symes, 2002) in everyday life as well as concerning parenting skills. This in turn may impact on the attachment or interaction between the child and parents.

Early intervention and outcome measures for parents

Primary outcome measures are those associated with change in the child diagnosed with ASD. These changes may be split into the categories of language, behaviour and social interaction. Secondary measures of outcome are those associated with parental changes. These may be related to stress, knowledge and confidence (Diggle et al., 2002). It has been argued that work solely utilising primary outcome measures does not consider the contribution made by external factors, such as family environment as well as the community

(Wolery & Garfinkle, 2002). The areas of parental stress, self-efficacy, mental health and satisfaction will be explored further here as important outcome variables.

Stress

Koegel and Koegel (2002) considered stress levels to be an important outcome measurement following early intervention for families of children with a diagnosis of ASD. They measured stress along with happiness and interest by taking 'Parental Composite Affect' ratings. This is not a standardised measure, but was adapted from similar scales also produced by the authors. Reliability measures were collected across the experimental phase of data collection for at least 33% of the sessions. Two independent observers recorded 'parental affect' during each 10 minutes of the phases of data collection. Six point rating scales were used for affect, and agreement was defined as the two observer ratings being no more than 1 point away from each other. Percentage reliability ratings ranged from 67% to 100% for the five parents observed. From these measures it was concluded that parents demonstrated an improvement in happiness, a decrease in stress levels and increased interest in their interaction with their children. The 'parental composite affect' ratings demonstrated stability in these variables across the phases of data collection (pre, post and 3-month follow-up).

The main outcome measure that has been repeatedly used when considering parental outcomes is the Parenting Stress Index ([PSI], Abidin, 1990). It appears that the short form has been the measure of choice for many researchers, however, the reasons for this have not been explained. The PSI has been used in

3 of the 12 studies reviewed here, in the short form (Engwall & MacPherson, 2003; Salt et al., 2002) and the original version (Smith et al., 2000). It appears to be the only standardised measure that has been utilised to evaluate parental outcome in early intervention. However, comparisons in results across the studies are difficult to complete because of varying designs and intervention packages administered.

Self-Efficacy

Sofronoff and Farbotko (2002) evaluate the impact of parent management training on parent self-efficacy for an older group of children diagnosed with Asperger's Syndrome. Hastings and Symes (2000) argue that there is a negative correlation between parental self-efficacy and child behaviour, with parents having lower self-efficacy when working with children with more severe symptoms and when feeling less supported. However, it is important to recognise that the Hastings and Symes study (2002) was solely with mothers. Sofronoff and Farbotko (2002) did include fathers in the analysis of self-efficacy. Results with fathers demonstrated that there was no change in self-efficacy at any point in time when measurement was taken (pre, post and 3-month follow-up). Suggestions for this are a difference in parenting role and the possibility that some of the fathers by admission and from therapist observation, were possibly displaying traits of Asperger's Syndrome themselves, possibly impacting on their parenting skills. However, these possibilities need to be explored in further research.

A limitation of the Sofronoff and Farbotko study (2002) concerned the self-efficacy measure used. This measure asked questions about the occurrence of behaviours within the previous month and parents were required to give a 'yes' or 'no' response. For each behaviour, parents were asked to rate their confidence in dealing with this behaviour from 0 (no confidence) to 5 (complete confidence). A mean self-efficacy score was then obtained by dividing the total confidence score for 'yes' behaviours by the total number of 'yes' behaviours.

This measurement of self-efficacy was designed solely for that study and the reliability and validity of the measure has not been determined. This measure was used for parents of children with Asperger's syndrome rather than covering children across the spectrum. The age range of these children was also higher (6 to 12 years) than the age range of any of the other children in the papers reviewed. This age range itself could mediate the relationship between self-efficacy and child outcome in intervention, although this would need further exploration. These children would have commenced school so parents would have been spending less time with the child, possibly facilitating parents' increased levels of energy to cope when the child is at home. Furthermore, parents may have developed relationships with other parents and communication with these parents may have normalised the parenting experience, thus decreasing the de-skilling that may occur when a parent feels that their general parenting skills are not working with their child who is diagnosed with ASD.

Although this paper was not evaluating one of the common types of early intervention programmes, it was useful to consider the role that self-efficacy may

play in moderating the relationship between use of the programme and successful outcome, as well as the possible relationship between parental and child outcome.

Mental Health

There is only one study that considers the mental health of parents (Bitsika & Sharpley, 2000). This study incorporates the pre and post measurement of depression and anxiety as well as measures of confidence and stress, following a parental support group aiming to train parents in specific stress management techniques. These four items measured were done so within the Parent Support Group Questionnaire that was specifically designed for the study itself. This was a revised measure based on findings from the previous study (Bitsika & Sharpley, 1999) for which no reliability and validity checks have been reported. Depression and anxiety was also measured through the administration of the Self-Rating Anxiety Scale (Zung, 1971) and the Self-Rating Depression Scale (Zung, 1965). Validity and reliability checks have been completed for these measures. It has been argued that the Self-Rating Depression Scale is superior to the Beck Depression Inventory and the MMPI Depression Scale when assessing depressed male psychiatric patients (Schaefer et al., 1985), yet this study was completed with mothers from a non-psychiatric background, making this argument irrelevant for the population studied.

Results from these measures demonstrated that there was no change in stress, anxiety and depression. A difficulty with this study is that different measures

were used at different assessment phases; some assessments were completed for retrospective, pre and post programme completion, in comparison to some assessments that were only completed pre and post session. This was the same for the assessments in the previous study completed by the same authors (Bitsika & Sharpley, 1999).

In the previous studies by Bitsika and Sharpley (1999 and 2000) questions were tailored to measure specific factors that the authors believed would be affected by participation in the support group that provided counselling. These factors were determined by previous consultation with only ten other parents who were not accessing the group but who were raising a child diagnosed with ASD.

Given that no statistical analyses were completed on these variables, it is difficult to determine the generalisability of these findings to the group that was being assessed for the studies. It may have been more beneficial to ask the parents in the groups themselves what they believed would be the most salient factors that would determine success following participation in the group.

Satisfaction with intervention/support

Smith et al. (2000) evaluated a Lovaas intervention (Lovaas, 1987), using a Parent Satisfaction Questionnaire to assess parental perceptions of child progress and satisfaction with services. This questionnaire was a 20 item written survey that was rated from 0 to 7 for each item. It was sent to parents to complete 2-3 year follow-up from intervention. Questionnaires were returned anonymously by mothers. This study was limited in the discussion of the findings gathered from

administration of this measure, although parents did report high levels of satisfaction with the intervention. Because these questionnaires were returned anonymously, correlation between parent and child outcome could not be completed.

Engwall and MacPherson (2003) designed “Early Bird”, Post and Follow-up Programme Questionnaires to determine enjoyment and overall satisfaction with “Early Bird” intervention groups as well as asking questions regarding what parents felt they had gained from the programme. They also administered self-designed local Pre and Post Programme Questionnaires. These questionnaires addressed the main goal of the treatment, being to increase learning. Parents were asked to rate their knowledge of autism, the term “ASD” and their understanding of their child’s communication and behaviour. The results from this questionnaire highlighted reasons for the decrease in PSI scores, being acquisition of relevant information, learning of new practical skills and the supportive environment that the group provided. All of these factors developed parents’ positive feelings about their parenting skills and increased their confidence in discussing their difficulties with professionals. These findings highlight the role that group support plays in increasing a parent’s ability to be able to seek and discuss with a professional, the difficulties they experience with their child.

There are only two studies that utilise interviews to determine outcome (Chandler et al., 2002; Whitaker, 2002). Chandler et al. (2002) completed interviews with parents 6 and 12 months into a post diagnostic support group, as

well as 6 months following completion of the intervention. The content of these semi-structured interviews was analysed using content analysis and was categorised by two independent researchers. The inter-researcher reliability was over 90%. The interview question themes covered the usefulness of different components of the diagnosis and intervention package and different benefits that parents believed they had gained. Six months into the intervention, parents were reporting the benefits of being given a clear approach, support and advice. They felt able to engage with their child, manage their child's behaviour and had a general understanding of ASD.

Whitaker (2002) presents very detailed findings from interviews completed with parents after they had left the service from which they were receiving the National Autism Society's "EarlyBird" package (Shields, 2001). This interview covered the diagnostic process, satisfaction with the process and the package and unmet needs. Parents were also asked to rate different aspects of the package on a scale of 'usefulness'. Much like the findings from the study by Engwall and MacPherson (2003), the support worker was viewed as useful because of the support provided to nurseries/schools and the practical strategies and education provided, which increased parents' understanding of their child's development and needs.

LIMITATIONS

Methodological issues

There are many methodological issues to consider when future research is conducted in this area. Only small sample sizes have been utilised to explore the needs and impact of early intervention for parents with children diagnosed with ASD. This is due to the time scale in which children are diagnosed, by which time it may be too late to address some of the initial needs that parents have following diagnosis, or even before a diagnosis is suspected or obtained. Often children are diagnosed in early childhood and possibly after they have started school. Until improvements are made in early diagnosis it is unlikely that sample sizes will change. (Diggle et al., 2002). One problem that is currently present with early diagnosis is a lack of screening measures that are specific and sensitive to ASD (Bryson, Rogers & Fombonne, 2003).

Another limitation with these studies is with the samples that are used. The country of origin, gender of the child and the parent, age of the child and diagnostic category used for the inclusion criteria, all varied. This makes it difficult to compare findings across studies.

A further limitation of these studies that decreases the opportunity to make comparisons, is that of the design of the studies. They range from single case to multiple baselines with various groups of participants. Control groups are different across studies, composed of parents of children with varying levels of

impairment, which parents themselves have reported as creating difficulties in being able to adapt some approaches to their individual needs. Other studies utilise exploratory designs; whilst being informative the statistical significance of the qualitative findings cannot be considered.

There are further difficulties with the outcome measures that have been used across these studies. A variety of measures are used, many of which are created by the authors for the purpose of evaluating the specific intervention that is being offered within the study, many excluding reliability and validity calculations for the measures. Some questionnaires and interview schedules are not semi-structured, further decreasing the exploration of individual experience rather than the authors' pre-conceived ideas of the impact that early intervention programmes are possibly having on parents.

There are also problems with timing of administration of outcome measures. Quite often measures are not administered throughout the treatment period. If this was done, confounding variable effects on outcome, for example, starting school, may be considered. Follow-up measures are quite often only administered 3-6 months following completion of an intervention programme. This makes it difficult to determine the long-term effectiveness of interventions (Diggle et al., 2002). Much longer follow-up studies are needed as well as prospective studies, identifying families who are at risk of having a child diagnosed with ASD and monitoring their changing needs over time, possibly from before diagnosis until possibly, after the child has started primary school.

Types of interventions

Of all the papers reviewed, only two specifically addressed the more popular intervention programmes that have been utilised and are detailed in the introduction of this review (Lovaas, addressed by Smith et al., 2000 and “Early Bird”, addressed by Engwall and MacPherson, 2003). Generalisation of findings from the studies cannot be made because they mainly focus on specific individualised intervention programmes that have not been administered in other settings or other countries. Further research needs to be completed evaluating these early intervention programmes both from a parent and child perspective, further developing the picture of the interaction between the two, as well as the moderating and mediating factors in outcome for both parties.

Within the papers reviewed, parents were only offered one intervention programme within certain settings; for the majority this was home based. It may be the case that certain aspects of different intervention programmes may or may not be suitable for different parents and further research needs to be completed exploring different parent and intervention variables in relation to parent and child outcome.

FUTURE DIRECTIONS FOR RESEARCH

It has been argued by Bryson et al. (2003) that the next generation of studies need to address the methodological flaws that have been present in previous early intervention research. The variables responsible for observed change in outcome

measures should be considered. Response to interventions, require comparison across interventions and environments as well as covering the whole spectrum of functioning of children diagnosed with ASD. Bryson et al. (2003) also argue that it is important to understand the mechanisms by which interaction between parent and child facilitates positive outcome for the child and the parent.

Finally, although measures of outcome have been used to monitor the core deficits/specific skill domains, that children with ASD may possibly have, such as difficulties in communication, socialisation and imagination, developmental difficulties, such as sleeping, eating and toileting have received little attention in terms of early intervention. There is literature on the prevalence of these difficulties, but not on intervention and the impact upon parents and children. This is important to consider because of the numbers of parents presenting to clinics seeking information and support regarding these developmental tasks. Although there is limited literature about these issues, parents are sharing and utilising various methods that do and do not work. It would be beneficial to study parents' experiences of support for their child's developmental difficulties within the research context. Results may also inform the structure and content of early intervention programmes, providing support specific to parental needs, for example in expanding the National Autistic Society's "Early Bird" programme.

SUMMARY

This review has highlighted researcher attempts to focus on the needs of parents of children diagnosed with ASD when they are accessing early intervention

programmes or support groups. The review has covered the range of research design, variables monitored and the samples used. The research also covers interventions aimed at addressing children's behavioural difficulties and more specific problems, for example with sleeping and providing post diagnosis support for parents. Interventions have been applied to single cases, individual families and groups of families, with children varying greatly in age at which intervention is offered. Research reviewed has also been completed within different settings and different countries. It is therefore difficult to compare findings across papers and to make generalisations for other families needs, as well as the impact of different intervention packages on stress, mental health and self-efficacy of parents.

Further research needs to be completed, utilising a combination of quantitative and qualitative designs, to address the clinical and statistical significance of findings within this field. These methodologies could be used to explore different intervention programmes and parental difficulties with facilitating different developmental milestones, for example feeding and toilet training. Qualitative methodologies need to be applied to increase the integrity of the findings regarding parental needs and outcomes, as well as to understand further the role of the family system in mediating outcomes for children utilising early intervention programmes. Quantitative methodologies may prove useful in determining the extent to which different interventions address parental needs, in different contexts, such as home, school and research settings. With the use of statistical analysis, the size of samples needs to increase, to minimise measurement error. It may be that multi-site interventions and evaluations could

be conducted, particularly for nationally available programmes such as “ Early
Bird.”

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Chapter II

The Toilet Training Process:

Experiences of Parents with Children Diagnosed with Autism Spectrum Disorder

Chapter word count (Excluding tables, figures, raw data and references): 5499

ABSTRACT

Currently there is limited research that explores parent's experiences of toilet training typically developing children. There has been even less focus on parent's experiences of toilet training children diagnosed with Autism Spectrum Disorder, whom it has been argued may have further difficulties with this task. The aim of this research is to explore parents' experiences of toilet training their child with a diagnosis of Autism Spectrum Disorder. A semi-structured interview was completed with nine parents; 8 mothers and 1 father, of children aged between 4-8 years, with a diagnosis of Autism Spectrum Disorder. The interviews were transcribed verbatim and were analysed using Interpretative Phenomenological Analysis (Smith & Osborn, 2003). Fourteen themes emerged and a relationship between them is presented in a preliminary model. These themes are discussed in relation to psychological theory and research, concluding with methodological limitations and future directions for research and clinical practice.

INTRODUCTION

Developmental Milestones in childhood

Throughout infancy and childhood there are many developmental tasks that need to be accomplished by the child. These can be categorised under physical growth, motor and language development, socialisation and cognitive development (Herbert, 2003). These tasks have been divided into stages and are accompanied by estimations of age for accomplishment of these stages (Green, 1992). The age ranges presented by Green (1992) act only as a guide and the author encourages parents to go at their child's own pace. Achieving milestones related to self-regulation such as sleeping, eating and toileting, is a complex process for which many aspects of each task may not progress smoothly. Whilst research has been conducted concerning eating and sleeping, toilet training has been a neglected area of research. This may be due to the sensitivity of the topic.

Toilet Training

Toilet training relies on the sufficient formation of nerve pathways being formed before the child is able to voluntarily control the bladder and the bowel (Green, 1992). Control of the bowel usually develops before control of the bladder (Herbert, 2003). Control of the bowel at night usually develops before control during the day. For bladder control this sequence is reversed with control during the day usually developing first. Girls generally attain bowel and bladder control faster than boys (Herbert, 1996). The consensus amongst clinicians is to wait for

the child to signal when they are ready to be toilet trained so that parents do not initiate toilet training too early or too late (Herbert, 2003). This is important because it is much harder to toilet train a child if it is not the optimum time for the child (Green, 1992).

Acceptable ages for attaining these skills are dependant on cultural values (Herbert, 2003). In Western cultures, not being toilet trained can have implications for the interaction between school staff and parents because staff sometimes inform parents that their child may not be accepted into school unless they are reasonably well toilet trained. This is often due to lack of resources available, such as time and facilities to support a child who has not yet been toilet trained. The Department of Health's "Good Practice in Continence Service" document (2000) states that children should not be excluded from pre-school and school educational activities because of continence problems. Although this is stated, parents presenting to clinics still report that this pressure is still placed on them to toilet train their child.

Elimination Disorders

When there is difficulty for a child in any part of the process of toilet training, this may be termed an elimination disorder (American Psychiatric Association, 1994). The two types of common disorders are Enuresis or Encopresis. Enuresis refers to incontinence in inappropriate places in children above the age of five years (Herbert, 1996). Encopresis is diagnosed in children who have soiling difficulties over the age of four years (American Psychiatric Association, 1994).

This is only diagnosed in the absence of physical causation, such as Hirschprung's disease, hypothyroidism, gastrointestinal disease and intestinal obstruction (Buchanan, 1992).

Enuresis

Enuresis can occur during the day; diurnal, or the night; nocturnal. In most cases these can occur together (Talay-Ongan, 1998). Primary Enuresis describes the problem being present from birth. If continence develops before the age of five years but then regresses, this is termed secondary Enuresis (Walker, 1995). With secondary Enuresis, a distinction can then be made between intentional and unintentional Enuresis, depending upon physical or psychological aetiologies (Murphy & Carr, 2000).

Encopresis

Much like Enuresis, Encopresis can be primary or secondary. Hersov (1994) and Sutton (1999) make a further distinction between retentive and non-retentive Encopresis. Retentive Encopresis refers to the child having an obstruction around which fluid leaks to create the soiling (Sutton, 1999). Non-retentive Encopresis suggests that the child is involuntarily incontinent of faeces, usually due to not being able to recognise the physical signals of the need to defecate (Sutton, 1999).

Toilet Training a Child with a Developmental Disorder

Toilet training can be a difficult developmental milestone to achieve for any child. If a child also has a developmental disorder this can further complicate the process of toilet training. Within the clinical setting, parents of children diagnosed with Autism Spectrum Disorder present with difficulties with the process of and completion of toilet training.

Encopresis and bowel problems have been observed as being very common in children diagnosed with Autism Spectrum Disorder (Dalrymple & Angrist, 1988). These authors have recommended that toilet training be completed with children as early as possible because remediation with adolescents with this problem is extremely difficult, if not impossible in some cases.

Autism Spectrum Disorder

Autism Spectrum Disorder (ASD) is a clinical term used to cover the diagnostic categories of Asperger's Disorder and Autistic Disorder within the Diagnostic and Statistical Manual for Mental Disorders, fourth edition ([DSM-IV] American Psychiatric Association, 1994). It is characterised by impairment in three key areas of development, namely reciprocal social interaction skills, communication and imagination. It is also characterised by stereotyped behaviours, interests and activities. These impairments result in difficulties with verbal and non-verbal communication, such as understanding body language and social cues. This can lead to problems with developing peer relationships and difficulties with social

or emotional reciprocity. There may be a delay or lack of verbal communication. If children can talk they often use repetitive language or demonstrate difficulty with initiating conversation with others. Children may also demonstrate a difficulty with symbolic or imaginative play.

Within both diagnostic groups of Autistic Disorder and Asperger's Disorder there is heterogeneity of level of impairment. However, due to the types of difficulties that these children have, estimates of milestone development for typically developing children may not be suitable for this group of children (Howlin, 1998).

The age of onset of attempting toilet training with children with a diagnosis of ASD can be found to be higher and may be accomplished later than for children without a developmental delay (Dalrymple & Ruble, 1992). It has been recommended that toilet training should not commence before 18 months of age and should become a priority for parents of children diagnosed with ASD by the age of four years (Wheeler, 1998). Children diagnosed with ASD may have difficulties with toilet training for many reasons, which will be discussed in the following section.

How difficulties interfere with toilet training

A child diagnosed with ASD may have a need for structure (American Psychiatric Association, 1994) and introducing toileting activities in the bathroom is a change in routine, which may lead to the child feeling anxious.

Changes in routine and using different bathrooms can lead to regression during toilet training. This may lead to additional difficulties when toilet training a child older than four or five years of age who has started school because the child will need to generalise the skills that they have learnt from using one bathroom at home to using another bathroom at school. Smooth transition during this period of time will rely on effective communication and collaboration between staff at school and parents. Szyndler (1996) recommends that children diagnosed with ASD should actually start toilet training when the child has started school so that the task can be shared. This creates a paradox when considering parental reports about pressure from school staff for the child to be toilet trained before they enter education.

Another possible difficulty during toilet training for a child diagnosed with ASD is that they may become fixated on certain aspects of the toilet or the bathroom such that they may forget the purpose of being in the bathroom. Common obsessive behaviours that have been reported by parents are the stuffing of toilets with toilet roll and constant flushing of the chain (Dalrymple & Ruble, 1992).

The child diagnosed with ASD may also have difficulties associated with sensory awareness. The child may not recognise bodily functions so cannot understand the bodily cues indicating the need to use the toilet. The child may also be distressed by certain sensory aspects of the toilet or bathroom for example how the toilet looks or smells (Wheeler, 1998).

An additional consideration may be that by delaying toilet training, children may become too reliant on wearing a nappy and that established habits may be more difficult to change in this population of children (Dalrymple & Angrist, 1988).

Interventions currently used

Whilst some interventions used with typically developing children are the same as those utilised with children with ASD, some of the interventions used have been modified to address the needs of children diagnosed with ASD.

A modified Azrin-Foxx model (Azrin & Foxx, 1971) has been used with children diagnosed with ASD who have toilet training difficulties (Luiselli, 1997; Cicero & Pfadt, 2002). The aim of this model is to address such things as scheduling toileting opportunities, increasing fluid intake and reinforcement for appropriate voiding. The modified version excludes the use of over correction and the training is completed at school as well as at home to overcome difficulties that children diagnosed with ASD may have in not being able to generalise skills across settings. (Luiselli, 1997).

Other behavioural interventions include bringing the child to the toilet at regular intervals until such a time when the time intervals that the child will usually urinate can be identified (Richman, 2001). With these behavioural approaches it is recommended that rewards be used along with verbal praise. By doing this it has been argued that the child will start to feel comfortable with receiving praise from another person. Using distraction techniques whilst the child is on the

toilet, so they do not request coming off the toilet too soon and rewarding the child for each step that they take closer to the toilet, can also be effective (Dalrymple & Ruble, 1992).

To facilitate the child's understanding of the toilet training process, verbal directions have also been presented to the child in a pictorial format or in the context of a social story (Wheeler, 1998). These methods focus on presenting material in a way that is manageable for the child diagnosed with ASD to understand in the context of their possible difficulties with receptive or expressive language.

Alarms have been used to address sensory awareness difficulties. These are placed in the child's pants and the alarm goes off when the child urinates. Therefore, the child is made aware of the bodily sensation of urination. The physical sensation of nappies may have created familiarity for elimination and exposure to the toilet whilst not wearing a nappy may inhibit elimination due to the toilet being very dissimilar to the nappy (Taylor et al., 1994). When this is the case, toilet training whilst the child wears no underwear is a useful strategy. However, if the child is being toilet trained at school this may not be appropriate. Furthermore, children with ASD are often hypersensitive to sound (Attwood, 1995). In this instance this intervention may create more difficulties than solutions.

Impact on parents

Caring for a child diagnosed with ASD may be very stressful for some parents (Hastings & Johnson, 2001; Koegel et al., 1992; Moes & Frea, 2002). If the child then has further difficulties during toilet training this may have a considerable impact on parents. Parents may experience further stress, which may impact on their confidence as a parent and the attachment that they have with their child. Whilst this may be the case, within the literature there is little consideration of parental experiences of toilet training and possible implications for the parent and the parent-child relationship.

Rankin (2000), who is a parent of a child with ASD, has introduced the only personal account that could be found of difficulties associated with toilet training. In this book she openly discusses the extent and impact that soiling has on her and the staff who care for her child. This one readily available personal account clearly demonstrates the impact on parents and the need to investigate this further within the research context.

AIMS OF THE STUDY

The purpose of this research is to develop an understanding of parent's experiences of toilet training a child who has been diagnosed with ASD.

Another aim is to attempt to conceptualise parents' experiences within a psychological framework. Finally it is aimed to consider future clinical and research implications based on the findings.

METHOD

Participants

Parents attending the local child mental health service were approached if their child met the inclusion criteria:

Children had to be aged between 4-8 years old; have a clinical diagnosis of ASD, following a multidisciplinary assessment based on the DSM-IV criteria for Autistic Disorder or Asperger's Disorder, also having no physical or co-morbid significant learning disabilities.

Nine parents; eight mothers and one father agreed to participate in the research. The father was interviewed in a joint interview with one of the mothers. These two parents were coded as participant 4. Table 2 details the demographic information for all participants' children, including information about toilet training.

Table 2: Demographic information for all participants' children

| Parent code number | Child details | | | | | |
|-----------------------------------|----------------------|---------------|-----------------------------|---|--|-------------------------------|
| | Age | Gender | Ordinal position | Family history of Autism Spectrum Disorder | Age toilet training started | Age achieved |
| 1 | 4 | M | First | Only child with ASD | 2 ¼ | 3 |
| 2 | 8 | M | Second | Second child | 2 ½ | 3 ½ |
| 3 | 5 | M | First | Only child | 2 | 4 |
| 4 | 5 | M | First | Only child | 3 | 4 ¼ |
| 5 | 7 | F | Fifth | Third child | 2 ½ | Nocturnal Enuresis |
| 6 | 4 | M | Third | Only Child | Not known | 3 |
| 7 | 7 | M | Third | Second Child | 2 ½ | 6 |
| 8 | 5 | F | First | Only Child | 2 ½ | Not achieved at all yet |

Methodology

A retrospective, semi-structured interview schedule was designed following the guidelines suggested by Smith (1995), after reading literature within the field and following discussion with professionals working within the area. The interview was semi-structured allowing exploration of areas that parents highlighted as being important for them.

This schedule was piloted on one parent who had previous experience with services and had an older child diagnosed with ASD. Questions were amended following this interview and feedback from the mother. A copy of the finalised list of questions can be found in appendix F. Results from the pilot interview are not included in the results of this study.

Procedure

Ethical approval for this research was obtained from Coventry University Ethics Committee and the Local Research Ethics Committee. A copy of the approval documentation can be found in appendix A.

Invitation letters (appendix C) were sent to 28 parents along with an information sheet (appendix D) and a consent form (appendix E). If parent's wished to participate in the research they were requested to return the consent form in the accompanying stamped addressed envelope. These parents were then contacted by telephone to arrange a suitable time to conduct the interview, preferably when

there were no distractions that would interfere with completion and recording of the interview.

All interviews were completed in the parents' homes and were audiotaped. Interviews lasted between 30-90 minutes. The complete interviews were later transcribed verbatim. Transcripts were sent to parents to check for errors in transcription. This was also done to allow parents to withdraw any response that they did not wish to be included in the analysis. No transcripts were returned for amendments or to have information withdrawn.

ANALYSIS

Interpretative Phenomenological Analysis (IPA) was selected to evaluate the content of the transcripts. This approach was deemed appropriate in meeting the aims of the research; exploring and understanding experiences of the participants and developing an understanding of their mental and social world by incorporating interpretation at every stage of analysis. The stages of analysis followed are summarised in appendix G. These stages were based on the guidelines presented by Smith (2003) but were adapted to incorporate creation of a possible conceptualisation of parents' experiences. This approach used an ideographic approach; starting with examples found in each individual transcript and slowly forming more general themes. Themes that were deemed to be salient for parents were included regardless of frequency. This approach in turn considers individual differences as well as generalisation across participants. An example of stage two of the analysis process can be seen in appendix H. This

demonstrates how key words were identified in the text followed by an initial list of superordinate themes.

Validity

Whilst using IPA it has been argued that the researcher needs to make explicit the conceptions and preconceptions that they have, from which they are working. They need to reflect on this throughout each stage of data collection and analysis (Smith, 1995). Continual reflection facilitates the researcher's ability to remain grounded in the original data whilst conceptualising the participant's experience through conducting diverse levels of abstraction. Smith (2004) suggests that levels of abstraction can range from those grounded within the text to such things as use of metaphor within the responses. These processes improve the quality of the research (Henwood & Pidgeon, 1992).

To develop these skills a reflective diary was maintained throughout the research coupled with attendance at frequent IPA consultation meetings with other researchers utilising the same method. Co-authors were also consulted throughout the whole research process. During meetings a "confirmability trail" (Erlandson et al., 1993) was presented to colleagues. It is also intended that triangulation of the data will be attempted by sharing interpretations with the participants before submission of the findings for publication.

Conceptions/Preconceptions

The author of this paper has knowledge of literature on the personal experiences of children and their parents with Enuresis and Encopresis. The author also has values and assumptions based upon personal experiences of secondary Enuresis, a developing knowledge base of toilet training in children who are typically developing and children diagnosed with ASD. The author has clinical experience of working with children diagnosed with ASD and their families. The author favours a Personal Construct Psychology approach (Kelly, 1955).

RESULTS

A total of 14 themes were found to be significant for parents. The themes and frequency of occurrence within the transcript are summarised in table 3. A summary table containing each occurrence of the themes within each transcript can be found in appendix I.

Table 3 – Themes and frequencies throughout the 8 transcripts

| THEME | THEME TITLES | FREQUENCY |
|--------------|--------------------------|------------------|
| 1 | Comparison with others | 73 |
| 2 | Information sharing | 40 |
| 3 | Social implications | 33 |
| 4 | Family functioning | 56 |
| 5 | Effective Support | 29 |
| 6 | Testing techniques | 53 |
| 7 | Awareness of stages | 63 |
| 8 | Child Centred Approaches | 69 |
| 9 | Intellectualisation | 24 |
| 10 | Minimising/Denial | 20 |
| 11 | Catastrophic thinking | 14 |
| 12 | Normalisation | 51 |
| 13 | Accepting | 27 |
| 14 | Emotions | 68 |

All of the themes presented in table 3 will now be described and examples given, using illustrative quotes from the transcripts. The participant number and line position of the quote will be stated at the end of each quote, for example 1.111 meaning participant one, line 111.

Theme 1 – Comparison with others

Parents often commented that their decision to begin the toilet training process was based on comparison with other parents and information presented to them in books regarding ‘norms’ of commencement of toilet training. Comparison with others continues throughout the process, with parents attempting to use comparison with peers and siblings to motivate their child to develop independence in toilet training and using pants instead of nappies.

“You know lots of people describing their experiences with their children and the things that they had to try. And, um, I remember reading about another child where there was a similar problem; the resistance to doing a poo. I don’t know whether that child was normal but it was in this book with the same issue about requesting a nappy. So I suppose it made me less worried about it...I knew that we weren’t unique. That we weren’t suffering alone. That people had all sorts of problems. It was nice to hear that and I talked to my friends as well. You know it wasn’t/it was straightforward for some but not for all. Some children wet the bed at night, persistently for a long time. You know, I don’t know what’s worse, having to put a nappy on a child to do a poo or having to get up in the night to change a bed. You know, it’s swings and roundabouts isn’t it? So talking to people did help me.” (1.182)

“If there’s like a character or whatever, um, you can maybe refer to that and say, “look” you know, “he doesn’t wear a nappy” you know, “he’s a

big boy now” and you know, “you’re getting bigger” and you know, “you don’t need a nappy anymore”. (4.616)

When toilet training is not achieved parents then compare their child to typically developing children or children who are diagnosed with ASD, which can either help or add further pressure on to the parent to achieve the toilet training task.

An example of this comparison is demonstrated:

“When you’re a parent suddenly everybody you know is doing the same job as you. Every single person you know is a clinical psychologist...and 90% of what you talk about is the work you do. It stays with you, it’s waiting. You’re trying to support each other. But actually a lot of the time you’re not...you’re just sitting there talking about your successes and if they haven’t succeeded in that they feel like a failure.” (3.909)

Theme 2 - Information Sharing

As well as making comparisons with others, parents talked about the direct advice they received from other parents and professionals, which again either helped or hindered:

“He didn’t want to go on the potty. Despite, you know/you know...put Thunderbirds stickers all over it, did everything, you know, that every book ever tells you to do...and...none of it worked.” (3.138)

“You know it...is an enormous sense of failure and...obviously all your friends are trying to help you and support you by telling you about how they did it...and it just seems...it should make you feel better. But you try all their methods and then they fail. And you end up feeling even worse really because you think they seem to do it so easily...and no-one else can understand why you’re failing, they’re all just telling you...how they succeeded.” (3.334)

When considering the help that professionals did or could give, it appears that any information that normalises difficulties is just as helpful as practical advice. However, there was a sense that professionals did not have the knowledge or advice that was specific to children diagnosed with ASD. Parents also suggested that proactive early advice, presenting the types of difficulties that may occur during toilet training, may prepare parents:

“When she said to me 1 in 10 children are not toilet trained by the time they’re 4. That just made me feel so good. Honestly...just that little statistic was such a relief....” (3.974)

“Went to see her and she said, “oh no you’ll probably find that there’s 3 or 4 in his class, boys especially aren’t dry at night...100% it’s very very common.” (7.852)

“I haven’t really spoken to the GP about it and this is gonna sound very cynical as well again, but I will. I just don’t think they’re that experienced with Autism, so I think what’s the point.” (8.566)

“So really, it’s just people knowing it’s going to be difficult and it’s going to take a long time...And try to sort of get that across to people in a positive way...I don’t know how you tell people positively that they’re going to have a rough time really (laugh).” (5.1099)

Theme 3 - Social implications

Very often parents expected or experienced exclusion from schools when their child was not toilet trained by the time they commenced attendance at nursery. There were also social implications for the parent when out with a child who needed to be changed throughout the day. As children grew older, parents reported that their child became concerned about the implications of having an accident when engaging in social activities with their peer group:

“Whereas the other nursery said he’s got to be toilet trained in 2 weeks time otherwise he can’t go into that class, he’s...got to stay behind. I’ve got a very bright child here...and to stay behind with the 2-year-olds because he’s not toilet trained is, you know, not acceptable really. Not acceptable at all for god’s sake.” (3.1133)

“Just as I was about to go out the door...I was living in a new area. I didn't know many people until I met this really nice girl. She said, “come along to this toddler group” and I sort of said, “oh I'm gonna make new friends”...“She's really nice”, I was quite looking forward to it, had the kids ready and M just pooped himself as soon as we got out the door and I had to bath...then C was covered in it/in the bathroom. You know, so we never got there basically. Things like that would happen...a lot...”

(3.242)

“He...did an enormous wee all over the floor in the middle of Woolworths and...you know on the floor, scrubbing away with the baby wipes. (3.294)

“She's more concerned now at 7½ of going for sleepovers....In nappies. That's where she's coming from...She wants to start going on sleepovers...Which is why I say, “well, training pants, they don't need to know. You can go into the bathroom...Nobody needs to know you're actually wearing one.” (5.1298)

Theme 4 – Family functioning

Throughout all of the interviews, family interaction and relationships were focused on. Siblings and parents were used as role models for teaching the child how to use the toilet.

“Occasionally I’d remind him, “look...wouldn’t you like to be like J, wouldn’t you like to be like J. He doesn’t wear nappies at night.” But obviously, I mean it’s very difficult because you’re putting pressure on the older child...As well in a respect. Because...you’re sort of making an example of them...And sometimes it’s not fair to sort...of put them on that pedestal.” (7.576)

Parents demonstrated empathy for their child’s difficulties, whilst also considering the impact that their child’s difficulties was having on all family members. Based on these considerations some parents were also able to consider the impact that they may be having on the child themselves:

“I think the...worst thing for a child on the spectrum who’s struggling as a parent gets impatient with them...I think that would be the very worst thing that could happen...Because they can spiral downwards...Into a situation where nothing really could...happen.” (5.584)

“Loads of hugs was the main thing; the first thing I tried actually. Big hugs, big reward. Load...of hugs but it totally over powered him considering he hated it. He didn’t want any hugs and that was that.” (3.412)

“And also if it impacts on the other children because then they’re gonna get picked on because...H’s you know, “your sister’s not toilet trained”. (8.763)

“And when you’ve got other children with you, they don’t...necessarily understand the process of what’s going on and why they’ve got to hang around and why they’ve suddenly got to go and find a toilet to do it/what you’ve got to do in the car.” (5.208)

“That’s why we’re separated now...That’s not the reason why, but...generally it was because he didn’t actually help me at all.” (3.937)

Theme 5 - Effective Support

Fathers were deemed important in providing support during the toilet training process, particularly if the child was a male. The most effective support provided by partners and professionals was collaborative:

“You know my partner was very helpful. It wasn’t just me...he’d just aim to do the same as me...he’d be persuading A to sit on the toilet. It wasn’t...a scary thing. You know, “just a few minutes for daddy”. That would make daddy really happy...”. He was doing the same things as me.” (1.208)

Parents also commented on the beneficial effects of proactive support, normalisation and preparation for difficulties that may occur:

“Educate the parents, I think...that’s really important and...Prepare them, ...give them forms as to how to deal with a child who soils themselves and...wets themselves...I think that should be first really. Educate the parent; try to help the parent first and then hopefully the parent can pass that on.” (2.337)

“Actually, you know, the best information I got was 1 in 10 kids aren’t toilet trained by the time they’re 4 and give up.” (3.1001)

“Raising the awareness with schools...Approaching parents and saying “well this is quite common.” (7.843)

“Provide advice and support from the beginning rather than waiting for the parent to approach.” (7.874)

Theme 6 - Testing techniques

Some parents were already prepared for the process to be difficult, either because of previous experiences or awareness of their child being “different” to other children and being able to address the child’s needs rather than be led by social comparison and social pressure. For the majority of parents, even those with this knowledge, difficulties led to helplessness with regards to knowing the best way to practically address the problems. Various techniques were tested and parents found it difficult to identify which method worked for their child. There appeared to be shock as children developed skills “over night” or things just

“clicked”, adding further to feelings of helplessness and lack of control over the whole process.

“It wasn’t really anything to do with us. It just kind of happened” (1.63)

“So I think we just tried everything, cos it was so difficult. We just tried everything. It’s quite hard to isolate what exactly it was that worked.”
(1.152)

As parents made several attempts, they realised the pressures to meet their own needs. For example, although there was the knowledge that pull-up pants were not effective toilet training tools, they were socially practical:

“Be tolerant and use whatever tools you’ve got and I think if...in toilet training, trainer pants great when you’re going out... You know brilliant. Because you can sit them on the toilet and pull them down easily... But not when you’re home and you’re not wanting them to get dry because they will just wee on them.” (5.487)

“You’re wearing...pull-ups and we’ll do it again when we get home. So I did what suited me. I tried to make life easy for myself. Yeah I wasn’t trying to be a martyr to the cause, you know.” (3.1292)

Theme 7 - Awareness of stages

Parents moved on to describing the developmental processes involved in toilet training. There was reflection on the child's sensory awareness of needing to go to the toilet, the child's ability to communicate the need to use the toilet and to report accidents, as well as the ability to control both the bowel and bladder.

There was still the sense in many cases that parents had the knowledge of the toilet training process but struggled to put this into practice. Parents seemed to find it difficult to gauge when their child was at various stages. There were also misconceptions about the child's behaviour during different stages of the toilet training process. Even when children would sit on the toilet, parents could not understand why their child would urinate or defecate immediately upon being taken off the toilet. This highlights how difficult parents found it to put theory into practice with their child:

“I've got frustrated because I've always thought the toilet training thing, they're either ready or they're not...But it does get very hard to know what to do next...And what to try next.” (5.62)

“Yes, trying to capture that...period of development, you know, when they suddenly realise that...they're dirty...When they're wet or whatever.” (6.383)

“She along with the other autistic ones didn’t seem to have the same feeling of not liking being dirty.” (5.14)

“To do a wee and yet you could sit him on the potty/ I know everyone says this about their children. This was more a true with M. But for 10/15 minutes reading a book he’d get up and wee all over the floor.” (3.448)

Theme 8 - Child Centred Approaches

Parents either having previously toilet trained a child or having completed the task for the first time, considered how they could have improved their role during toilet training. Parents examined the adjustments they would have to make when toilet training a child with the difficulties associated with ASD. Parents suggested changing how the process is communicated to the child and providing rewards that are more meaningful for the child; the main aim of these approaches being to address the child’s needs and support them:

“In fact/in a way, if I hadn’t read any of those books. If I just sat down and thought about M and what he was like, I would have had a lot more success. You know...I’d tried...everyone else’s techniques that they’d used on their kids that had worked. I’d have been much much better off if just thinking about the sort of person that he was...and what he would have responded to and...my own kind of instincts.” (3.482)

“So we’d written her a social story...And H now will do everything. She will sit on the toilet, she’ll pull down her pants, she’ll wipe her bottom, she’ll pull up her pants. She’ll do everything apart from go to the toilet.” (8.74)

“Well we had to sort of motivate him by saying, “look if you sit on the toilet and let mummy read a book, we will x”. So we tried to add other motivational, sort of inducements. Motivators that we knew would work for him, like foodstuffs or playing games that he liked or videos that he liked.” (1.140)

“We tend to have a bit of a laugh and a joke really. I tickle him up the stairs until he goes into the bathroom. Just try and make it as though it’s a good thing to do and a positive thing to do.” (7.247)

“Really try to make the child feel OK.” (2.283)

Theme 9 – Intellectualisation

Throughout most of the process parents struggled with trying to understand some aspect of the process and how they and their child were developing and coping with it. They defended the services that were offered by rationalising why staff were unable to address the child’s needs. They were also able to think about their problems in relation to their child having a diagnosis of ASD:

“Every parent that you talk to that tells you about the success and how they achieved it with their children and all the rest of it; basically their child wanted to do it...Of course it’s bloody easy if your child wants to do it...if your child actively doesn’t want to do it because they really; they don’t have a desire to please you...Basically I think...that’s what I remember feeling at the time. Other children want to please their parents.” (3.194)

“I don’t really understand the psychology behind why he wasn’t wetting himself when we were out and he was when we were at home. He just didn’t seem to care. I mean he must have cared that he didn’t wet himself when he was out. But I don’t know. He was just busy.” (3.279)

“But ultimately the mainstream school with 30 kids in class can’t deal with a child who wets themselves 5 times a day in the classroom. So she had to leave mainstream school...” (3.1031)

“It’s just that I’m rationalising the fact that I can’t cope.” (6.175)

Theme 10 - Minimising

For some parents there appeared to be an emotional detachment from the experience; a dismissal of progress made or denial of the extent of the problems or the impact that the difficulties were having upon them:

“I think...twice he did actually wee in the potty...Because he was just tired actually. Really really tired...it didn't in any way contribute to him trying to sit on the potty again.” (3.442)

Dad – “We weren't concerned at all.” (4.376)

“There's nothing personal about my GP...I think if you've...got an ongoing, long-term problem. Then I would hope that...if you didn't do it then your health visitor would prod you to do it; to go...Get it checked out that there is nothing physical that is causing...While I was nowhere near that stage.” (6.548)

“I definitely think I've got quite a tough skin and I sort of shrug my shoulders and think “well, you know...that's the way life is really” (7.448)

“In fact...one of my friends said to me, “oh, how does H get on with other children about, you know” and to be honest I've not asked them at school because I don't know whether it's that I don't want to know...Or whether. There's so many other issues. To me that isn't the biggest problem.” (8.177)

Theme 11 – Catastrophic Thinking

For some parents the whole experience appeared to be overwhelming. For these parents there were exaggerations and expansion of detail of experiences in order to demonstrate just why the whole process was so difficult and demonstrated exactly why support and advice would be beneficial for these parents:

“A nightmare.” (3.3)

“Extremely stressful. Quite disturbing...a massive, massive failure.”
(3.8)

Theme 12 – Normalisation

As parents were gaining knowledge about toilet training and about ASD they were able to normalise the experiences and difficulties that they were having, particularly in relation to the diagnosis of ASD. However, for some parents it appeared to be more manageable if they could normalise the difficulties that they were having if they regarded it as being a problem related to the personality of the child:

“You think you’re a little island all on your own to realise that you’re not...you’re not individual...in this problem. I mean these children she said it was very common for children of all...even normal children.”
(7.855)

“But I think it’s...helped/it helps a lot...knowing. I know a lot of people don’t like labels and they don’t feel it is necessary. But my personal point of view is that if you don’t know what you are dealing with, how can you deal with it?...Yes I don’t agree with labels. It’s not fair. But on the other hand it answers a lot of questions...At the end of the day these children will be adults in an adult world...In some form or fashion. How can you prepare them for that adequately.” (7.755)

“You can’t be positive when you’re wiping up poo all over the floor and carpet and the toys and...And then 5 minutes later they just wee all over the floor again.” (3.752)

“I think we put it down to his anxiety/him being an anxious child.”
(2.395)

Theme 13 – Accepting

Parents demonstrated the importance of being prepared for toilet training. This preparation increased parents’ acceptance of the process. Furthermore, acceptance from other people within the community was important to parents. One parent who had many years experience of dealing with toilet training difficulties, demonstrated the need to initially personally accept it and then take responsibility to demonstrate acceptance, so that society can learn how to do this:

“It’s not an easy process, so you just have to accept that and decide that you’re going to...Be tolerant.” (5.484)

“We just accepted that...when we first started, that we were going to have wee on the carpet.” (1.206)

“You’ve got to, not necessarily be proud but you’ve got to be honest and forthright and up front...If your child’s got difficulties. What’s the point of hiding behind them...Or hiding your child behind them? If you’re honest and open...I’ve found people are very understanding...And very accommodating.” (7.387)

“What’s the point of blanketing it over and hiding it. If he’s got a problem. Yeah don’t broadcast it, but you make people aware...raising awareness of anything, improves people’s knowledge....And it’s their ability to accept things...For what they are.” (7.479)

“At pre school where they were absolutely fantastic and said, “don’t worry bring him in with...nappies on, we’ll still accept him”. (3.74)

Theme 14 - Emotions

Parents reflected upon their own feelings and those of their child. Difficult feelings ranged from shame and embarrassment to frustration. One parent openly expressed her anger towards other parents.

“You could see the anxiety; he was crying and getting really worked up.”
(1.110)

“All down his trousers and everything, you know...I just didn’t have
to...kind of hygiene wise I didn’t have to deal with the same kind of
mess.” (3.1274)

I...found it horrendous, you know. I just didn’t like the mess.” (8.412)

“Oh, it’s just not pleasant is it?” (8.517)

“I suppose I was a little frustrated. Exasperated, you know...worn out by
it.” (1.235)

“Because sometimes I would get annoyed.” (3.226)

“And I think, I don’t know, I shouldn’t really speak for (husband) but
she’s got some trousers that are quite short and it bothers him that you
can see her nappy.” (8.453)

“You’re initial reaction is to be embarrassed and, um, ashamed that your
child is like that.” (7.379)

“It doesn’t work anyway does it? All these bloody people that...present you with some incredibly outgoing girl that does acting and ballet and blah...Every f***ing class under the sun. They make you feel like a right failure because your children aren’t doing that.” (3.796)

In the later stages of the interviews, regret and guilt were also expressed as well as fear of future toilet training with siblings:

“You know, finish it there. I think...if I’d had that attitude a lot earlier...I don’t think I would have the guilt coming in now. But you do...feel guilty that perhaps if I’d dealt with it differently, earlier, it may not have gone on for so long.” (2.290)

“I saw it completely differently. I was also terrified of it. Really terrified.” (3.1234)

Parents found it difficult to reflect upon positive aspects of their experience. Positive emotions were experienced in relation to having completed toilet training and it being so negative. Whilst parents were relieved that the task was completed, some also expressed pride in their child for having achieved a task that was clearly difficult for them.

“Thank god that’s over.” (3.259)

“So...we were really pleased. We felt we’d cracked this huge hurdle. I mean we heaved a sigh of relief and were really pleased with ourselves.” (1.246)

“So the positives that come from toilet training a kid like N...Really comes from the fact that it’s been so negative...And any positives send you into a state of total ecstasy.” (5.567)

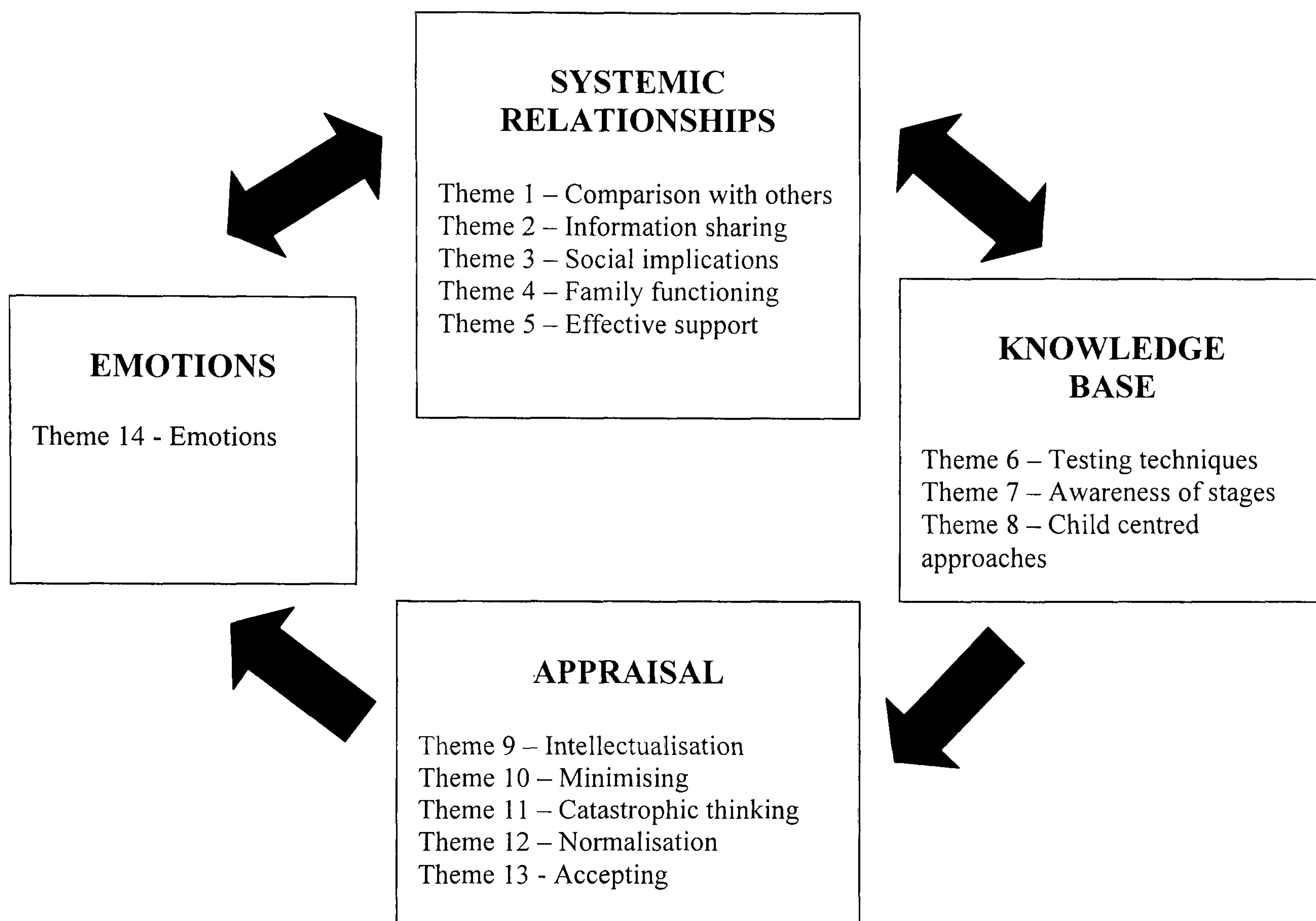
“But on the positive side it’s actually seeing the progression and seeing him learning those skills...And becoming more independent in his way...coping with these matters.” (7.279)

“It was all very gratifying when we had a dry day...And you know she would always be quite pleased with herself. She wasn’t upset if she didn’t but she’d be quite pleased with herself if she did.” (5.277)

CONCEPTUALISATION OF PARENTS’ EXPERIENCES

Figure 1 demonstrates a conceptualisation of parent’s experiences based upon the themes that emerged from the transcripts. The original fourteen themes were condensed under four master groupings that best demonstrated the process that parents went through over time. The master groupings are presented in the model highlighting the position of the original fourteen themes.

Figure 1 – Conceptualisation of parents’ toilet training experience



This model illustrates an interactive, cyclical process that develops over time.

Parents reflected on the period of time from before commencing toilet training to considering toilet training other children in the future. During this time period parents will have gone through the model in a variety of ways and a number of times. Parental experience usually commences in the systemic relationships master grouping of themes.

A parent’s decision to start toilet training is influenced by factors within the community and the family (themes 1 and 4). Depending upon advice and information received from professionals or other parents (theme 2) different

toilet training techniques are attempted (theme 6). When testing techniques, appraisals are made about the success or failure of these (themes 9-12).

Support during this time (theme 5) can be beneficial in protecting parents from difficult emotions (theme 14). However, parents still feel under pressure at this time to complete the task because of suggestions from school (theme 3) that children are excluded unless they are toilet trained. The child's increasing age also causes concerns with regards to the consequences this may have for the child and their siblings (themes 3 and 4).

Due to the difficult emotions that parents may have in relation to the child's difficulties in achieving tasks, they become aware that these emotions may be projected onto the child (theme 4). This awareness may increase the frequency of further difficult emotions for both the parent and the child (theme 14). Parents develop awareness of the tasks that the child needs to accomplish in order to achieve toilet training (theme 7). This awareness may lead to acceptance that the process will be difficult (theme 13) or further protective appraisal, such as intellectualisation (theme 9), minimising (theme 10) or normalisation. However, some parents may develop catastrophic thinking (theme 11) whilst struggling to put theory into practice.

Throughout the whole process positive emotions are not experienced until the toilet training task is completed (theme 14). Whilst some parents were able to accept the process or were able to meet their child's individual needs whilst not conforming to social pressure (theme 1), other parents struggled to have a child-

centred approach (theme 8). With hindsight and based on the experiences they were discussing, parents were able to reflect on doing this in the future.

DISCUSSION

The area investigated in this paper is under-researched so using a qualitative methodology was a useful starting point to build on in future research. From the results of this research wider scale studies could be considered for quantitative studies. It may also be useful to explore further the themes that emerged from this study to further understand these experiences and to develop the conceptualisation of parents' experiences.

The results of this study reflect similarities with a paper exploring the toilet training experiences of parents of typically developing children (Hauck, 1991). One major theme that was present in this study but not the paper by Hauck (1991) was the pressure placed on parents by nursery school staff to start toilet training. Children are no longer allowed to be excluded from school (Department of Health, 2000), so this was an unexpected finding. Parents reasoned that this pressure was due to a lack of resources in schools to address toilet training needs of children.

Only one group of parents were interviewed and these results are an interpretation of their experiences. In order to learn more about other parents' experiences, this research needs to be replicated with other groups of parents, to

explore factors that may be pertinent to families from different socio-economic and cultural backgrounds.

The children described in this study developed toilet training slightly later than the suggested 'norm' for typically developing children (Green, 1992), which supports the findings for children with ASD (Dalrymple & Ruble, 1992).

Consistent with the pattern of diagnosis of ASD (Wing, 1996), the sample in this study consisted of more boys than girls. In order to determine gender effect on toileting delay there needs to be further exploration of parents' experiences toilet training girls diagnosed with ASD.

The children that parents discussed were also in different ordinal positions, which may again have impacted on the parents' experience. It would be useful to complete research exploring the contribution of all of these factors to subjective experience of toilet training.

Most parents were unaware that their child had ASD when toilet training but some mothers benefited from having other insight of the difficulties associated with ASD having already had a child diagnosed with this disorder. Future research would benefit from completing a prospective study for those children who may be at a risk of being diagnosed with ASD to determine exactly how subjective experience is influenced by having a diagnosis and not having a diagnosis. All parents within this research had received a diagnosis when they were interviewed. This makes it difficult to determine how they experienced toilet training in 'real time', when they were recalling their experiences from an

informed perspective about ASD, which they would not have known when they were toilet training their child.

Finally there was only one father interviewed, so further exploration of paternal views may be beneficial in addressing the importance of fathers being used as role models to toilet train boys. Mothers in this sample suggested that it was important but there was a contradiction when they reported the difficulties that their child had with observational learning.

CLINICAL IMPLICATIONS

The results of this study highlight the need for school staff to be provided with the necessary resources, support and education for supporting all children with toilet training difficulties. Wheeler (1998) recommends that toilet training be a priority for children with ASD when they are four years old. If this is the norm for children with ASD then this further supports the need for resources and education for nursery staff to support parents and children during this process.

There is limited information that is specific to children diagnosed with ASD and quite often the diagnosis follows completion of the toilet training process. By the time that parents receive diagnosis specific support, advice and information they have already experienced self-blame and/or externalising blame, leading to isolation and parents not seeking help during this developmental period.

There is a need to educate and provide other professionals with the resources to give to parents who access their services. Parents need to be sign-posted to

support groups that address their specific difficulties, providing a validating and normalising experience, which is something that these parents had rarely received. This may best be provided by early intervention support groups, for example, “Early Bird” (Shields, 2001).

Some parents are equipped to be attuned with their child’s individual needs and resilient enough to resist social pressure. However, for parents for example who are struggling because it is their first child, support, advice and information sharing that normalises the problems, is required. As parents themselves have argued, professionals need to be more proactive and need to prepare parents for difficulties that may arise.

It may be beneficial for Health Visitors to prepare all parents for the possibility of the types of problems that may occur during this developmental period. This may encourage parents to approach professionals, such as their GP, should the problem occur, as the child grows older. Coupled with this is the fact that the parents may also experience difficulties during different developmental tasks (Wing, 1996). Having early access to professionals will enable parents to access further support, possibly by being referred to an early intervention parent support group. By addressing these parental needs as soon as they arise it may decrease the negative impact that this experience may have upon them and the whole family.

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Chapter III

Achieving Toileting Success:

Personal Account of a Child with Asperger's Syndrome

Chapter word count (Excluding tables, figures, raw data and references): 3837

ABSTRACT

There is extensive literature regarding the best practices whilst toilet training a typically developing child, with limited literature specifically for children with a developmental difficulty such as Asperger's Syndrome. However, there is no literature regarding the personal experiences of these children. The aim of this research is to examine the experience of a child with Asperger's Syndrome being toilet trained. A semi-structured interview was conducted with a 9-year-old girl who had completed all toilet training stages, having experienced secondary Enuresis during her infancy. The interview was transcribed verbatim and analysed using the ideographic case study approach to Interpretative Phenomenological Analysis (Smith et al., 1999). Five superordinate themes emerged and a possible relationship between these themes was presented in a model. These themes are discussed in relation to psychological theory and research, concluding with limitations and future directions for research and clinical practice.

INTRODUCTION

The only personal accounts of difficulties with the development of bowel and bladder control development are those related to more severe problems such as Enuresis and Encopresis, present in typically developing children. Enuresis is defined as difficulties in developing bladder control above the age of five years, in the absence of any physical cause (Herbert, 1996). A broad definition of Encopresis, irrespective of aetiology, applies to a child who soils themselves either during the day or night, over the age of four years but before the age of sixteen years (Herbert, 1996).

Research suggests that Enuresis may lead to humiliation, social isolation, fear of detection and a sense of immaturity (Anon, 1987; Butler, 1987 and 1998; Butler et al., 1994). Children with these difficulties are often aware of these social and emotional consequences. They construe their behaviours in more problematic terms, internalising them and feeling to blame for their difficulties (Robinson et al., 2003). As a result of this, they may fear the problem being discovered, feel different from others and avoid sleeping at friend's homes (Butler et al., 1994) even though they quite often present as apparently indifferent about their problems (Butler, 2001; Schaeffer, 1979). Additional problems such as being bullied (Anon, 1987; Williams et al., 1996) and having low self-esteem (Butler, 1998 and 2004; Panides & Ziller, 1981), both in the areas of perceived social competence (Butler et al., 1994) and physical appearance (Moffatt, 1994) have been described. It has been argued that if

low self-esteem persists then later psychiatric dysfunctions and social adjustment problems may be expected (Hagglof et al., 1998).

Within the family some children may feel that they are less preferred by their parents in relation to their siblings (Panides & Ziller, 1981) and may often be teased by their siblings (Butler et al., 1988 and 1990). Researchers have disputed how this teasing may lead to improvement in treatment outcome (Butler et al., 1988; Butler et al., 1990; Gorodzinsky et al., 1987). Mothers are more likely than fathers to become upset if their child has these difficulties (Wagner & Geffken, 1986). Some parents may struggle to tolerate the difficulties and may approach the problem with an overall feeling of helplessness (Butler & McKenna, 2002). Some parents, believing that the child has some control over the problem may become angry, annoyed or intolerant. Occasionally this leads to punitive means of coping with the accidents that occur (Haque et al., 1981) or withdrawal from treatment (Butler et al., 1988). In severe conditions within high-risk families, it has been suggested that difficulties with toilet training can be one of the factors associated with fatal abuse from parents (Barton & Schmitt, 1987).

Within the clinical setting it has become apparent that not achieving toilet training by school age can lead to exclusion from school settings, which may then impact on educational achievement. More recently the Department of Health's "Good Practice in Continence Services" document (Department of Health, 2000) clearly states that "Health and Local Authorities should introduce arrangements that ensure children

are not excluded from normal pre-school and school educational activities, solely because they are incontinent” (point 6.1). Health services may, therefore, play a role in informing educational services about the best way to meet the needs of children with these difficulties when they enter education.

It has been noted that children diagnosed with Autism Spectrum Disorder (ASD) have difficulties during the toilet training process (Wheeler, 1998). Some of the problems that these children have may be due to developmental difficulties associated with Asperger's Syndrome or Autism (Wheeler, 1998; William et al., 2004). These difficulties are associated with problems with communication, social and sensory awareness, rigidity and need for routine, motor planning difficulties and possible additional learning difficulties. Having these types of difficulties can have major implications for children and their families, on a practical, psychological and educational level (Wheeler, 1998; William et al., 2004). Whilst there have been numerous personal accounts of Autism (Grandin, 1996; Williams, 1998) and Asperger's Syndrome (Hall, 2000; Holliday Willey, 1999; Jackson, 2001 and 2002) these have not addressed the subjective impact that problems with toilet training might have. However, Matthews and Williams (2000) do comment on personal difficulties that children with ASD may have with toilet training and going to the bathroom, whilst offering solutions. Joan Matthews is the mother of James Williams, who is an 11 year old boy with ASD. In their book (Matthews & Williams, 2000) Joan Matthews presents hypothetical thoughts that her son may have, whilst James directly reports on only one difficulty, that of 'holding'.

The aim of this case study is to examine the subjective experience of the toilet training process for a child with developmental difficulties. By adopting such an approach it is hoped that this will help to develop effective ways of improving training and access to services for children having difficulties with this developmental stage. Consideration of personal experiences enables access to the constructions that a child has of being dry and wet as well as their views of the advantages and disadvantages of these experiences (Butler et al., 1990). This may in turn facilitate understanding of the treatment processes (Llewellyn, 1988).

In order to retain anonymity the name of this child and all identifying information have been altered or excluded throughout this case study.

METHOD

Participant

Lara is a 9 year old female, from a white, middle class background. She has a number of siblings, her ordinal position in the family being equal third with her twin. At four years of age she was diagnosed by the local child mental health service with Asperger's Syndrome based on the criteria of the International Classification of Mental and Behavioural Disorder ([ICD-10] World Health Organisation, 1994). There is a family history of Asperger's Syndrome; Lara's uncle has a similar diagnosis. Following cognitive assessment she was diagnosed with Asperger's

Syndrome because of her relatively high level of functioning. The defining symptoms that she had were difficulties remaining focused on a task, minimal expressive and receptive language difficulties and lack of imagination. She would become distressed with a change in routine or when placed in a group situation. She preferred one-to-one contact, engaged in independent play for the majority of the time and when engaging in play with others would always follow their lead.

Toilet training was comparable with the norms for achievement for typically developing children, whilst the order of achievement was not consistent for bowel control. Toilet training commenced when Lara was 2½ years old. Lara developed overall bowel control during the day at 3 years and during the night at 4 years, having the odd accident until she was 6 years old. Because of these difficulties her mother kept her in trainer pants until she was 6 years old. Lara developed bladder control during both the day and night when she was 3 years old. From the age of 5 to 6 years she developed secondary nocturnal Enuresis following a house move.

Design

It is difficult to interview a child whilst they are experiencing the toilet training process due to the early age at which this process is commenced. Therefore, a retrospective design, interviewing an older child, was more suited to exploring this sensitive topic.

Questions for this interview were developed using the suggestions by Smith and Osborn (2003). Following a review of the literature, broad areas of interest were used to develop the questions. A speech and language therapist, a clinical psychologist specialising in working with children diagnosed with ASD, the ethics committee and Lara's mother were then consulted during the development of the questions so that they were pitched at a level that was suitable for Lara's functioning. Lara's mother thus had knowledge of the structure of the interview and consented to the questions that would be asked.

A semi-structured interview was utilised to explore any salient topics that emerged. The order of administration of the questions was flexible to facilitate Lara's engagement in the interview and to decrease disruption in the flow of questions. A copy of the interview questions can be found in appendix L.

Procedure

Before the interview was conducted, the aims of the research were explained to Lara and she was given an information sheet that she could keep to refer to in the future should she want to. A copy of this information sheet can be found in appendix J. Her right to withdraw from the research and to refuse participation in the research was explained to her. When this task was completed Lara signed a consent form which was then signed by her mother. A copy of this consent form can be found in appendix K.

The interview was then completed in Lara's home and was tape-recorded. The interview lasted approximately 30 minutes. During this time her siblings were in another room. Her mother continued to stay in the room but at a distance until Lara requested some assistance to answer one of the questions, concerning the age when she commenced the toilet training process.

The interview was then transcribed verbatim and a copy of the transcription was sent to Lara with a thank you letter (appendix M). The sending of the letter was preceded with a phone call to Lara's mother to reiterate the purpose of the task, which was explained to Lara herself during the debriefing phase following the interview. At this time she was given the opportunity to comment on any errors or to request that any of the contents of the interview transcript be withdrawn from the analysis and write up of the study. This action was taken to reiterate her rights as a participant and considered especially important given the sensitive nature of the material that was covered. She did not request any amendments or exclusions from the original transcription, when contacted after one week of the transcript and letter being sent to her.

ANALYSIS

The interview was analysed using the ideographic case study approach of Interpretative Phenomenological Analysis (IPA), (Smith et al., 1999). This method has been described as effective when interviewing children about their personal experiences of a particular phenomenon (Smith, 2004). IPA accepts that in order to understand the participant's world, exploration of particular phenomena within this world will rely on interpretations of the researcher based on their own views and the interaction between the researcher and the participant (Willig, 2001). This was believed to be the most suitable method to adopt based on these assumptions and given the aims of this study.

The analysis was completed in a series of stages adapted from Smith and Osborn (2003). These stages are outlined in table 4.

Table 4: Summary of the process of theme formation (Smith and Osborn, 2003)

| Stage | Stage Description |
|---|---|
| 1 – Identifying themes | Make preliminary notes using key words to capture the essential contents of the text. Abstract theme titles will then be developed. |
| 2 – Searching for connections between themes | Whilst these themes are developing, connections will be made between emerging themes throughout the whole transcript. |
| 3 – Creating a master list of themes | It may then be possible to pull together the initial categories to form superordinate themes. A cyclical process will be used for the development and changing of themes so they remain closely related to the original transcript. |
| 4 – Creating a table of themes | A table of themes ordered in a coherent manner will be created. Frequency of appearance within the transcript will be noted. |
| 5 – Narrative account of themes | Themes will then be written as a narrative account of Lara's experience of toilet training. This narrative will include quotes from the transcript to illustrate the themes (including line number e.g. 233 = line 233). |
| 6 – Conceptualisation of experience | A diagrammatic representation of Lara's experiences will be created to demonstrate an understanding of how the themes possibly link in such a way to create Lara's experience. |

An extract from the interview transcript is used as an example to demonstrate stages two and four of the analysis. This extract can be found in appendix N. Initial

clustering of themes and the superordinate themes created can be found in appendix O.

Analysis of the transcripts revealed that Lara often mixed up the tenses she was using to recall information. In these instances it was difficult to determine whom she was referring to. Her time frame was sometimes confusing, but it was clear that she had not rehearsed responses because she was readily able to answer additional questions and did not seem to rely on socially desirable responses.

RESULTS

A total of 5 superordinate themes illustrated Lara's experience. The themes and frequency of occurrence within the transcript are summarised in table 5. All of these themes will be discussed and quotes from the transcript will be included to illustrate the themes.

Table 5– Themes and frequencies throughout the transcript

| Theme | Theme title | Frequency |
|-------|--|-----------|
| 1 | Difficulties throughout the toilet training experience | 16 |
| 2 | Toilet training techniques | 21 |
| 3 | Personal consequences | 17 |
| 4 | Social consequences | 10 |
| 5 | Emotional consequences | 17 |

Theme 1 – Difficulties throughout the toilet training process

Throughout the interview Lara was asked to comment on things that she recalled about her potty and toilet training experiences. Based on her own experiences she was then invited to share what she believed could be done for other children going through this developmental process.

Throughout the interview Lara reflected on the difficulties that she had with the toilet training process. She demonstrated an ability to recall numerous toileting accidents. Some of these accidents were possibly related to control whilst some may have related to sensation:

“I was standing over there and I pooed my pants...I was too big for the potty so I was just about to/oh no I had the runs and...I thought I...wasn't doing anything. I didn't feel it so...I pooed in my pants by accident.” (129)

“Oh and I do remember another time. When we were in a bungalow about two years ago I woke up and I...think I was sleep walking and I pooed on the floor.” (159)

“But once I...wet one bed....and I was in another bed and I wet that bed as well...So that didn't feel very good either.” (439)

“But I don't normally poo. I don't know why...I just normally wee.” (326)

“And I wasn't covered in poo, but I didn't feel/it was. Well when I felt it.... I felt unusual.” (215)

The only explanation that Lara could find for her continued difficulties at night was:

“Sometimes I dreamt about water so it made me wee (251)...sometimes looking at a fish tank or swimming in the sea (265)... and drinking made me...wee because I was thinking of liquids.” (267)

Theme 2 – Toilet training techniques

Throughout the interview Lara commented on things that did and did not work. In addition to answering direct questions concerning what advice she would give to other children, she suggested what other people could do to help children with problems similar to the ones that she had experienced. Whilst considering these issues, the dynamic relationship between parent and child and the joint working involved in toilet training was raised. From having such a positive relationship with her mother she was able to offer solutions for improving the toilet training experience:

Interviewer: “Was there anything that helped you at night to stop having an accident?”

Lara: Well I said to my mum last night that I could have a potty every where so I didn’t wee.” (306)

“If I had a toilet...you could press this button...and it would rise you up to get on to the toilet so that would make going to the toilet fun.” (479)

“If mum say’s “hup 2, 3, 4, hup 2, 3, 4” and...then they...get into the toilet and they just make it fun for children.” (493)

“Well. You’ll...just have to be calm about it.” (559)

“Probably comfort me and make me feel good.” (431)

She also had recommendations for GPs:

“The doctor, either make you feel better...well he could say...his daughter or son has the same problem then that would make...the patient feel a little bit better so...they won’t feel left out.” (522)

This suggestion relates to the concept of normalisation of difficulties, which was reflected in her comments about what she would say to another child in a similar position to herself:

“I used to have accidents as well.” (570)

“Well, you could say that I’m sure loads of other people would do the same thing...so you shouldn’t feel left out.” (578)

“I used to do it as well...I had the same experience and I know how you feel...and I could help them.” (586)

A very influential factor in the effective toilet training experiences of Lara was the support that was provided by her family:

“I think it was only my mum and dad that were up cos when my dad was cleaning me I think my mum was changing my bed.” (202)

“Well sometimes they used to help me...if they saw that a drip was coming... then they would just quickly whiz me to the potty.” (394)

“I woke my sister up...She'll take me and clean my bed up.” (294)

“My Nana said, "It's OK...don't worry about it.” (663)

In relation to reactions to accidents Lara, also commented on emotions that were counterproductive and might have a negative impact on the child:

“Well if the mums...didn't...make you feel good and they just took their hand and just...scraped them along the floor then that wouldn't be nice...That won't be helpful.” (502)

Theme 3 – Personal Consequences

Lara talked openly about the immediate effects on her when she had an accident.

The negative consequences that she reported were similar to those reported in the study conducted by Butler et al. (1990), such as the immediate physical implications.

Due to Lara wearing pants in bed until the age of six years, these became uncomfortable at night, as she grew bigger:

“They hurt me...They hurt...my bum and they...were too tight on the side.”

(627)

As well as immediate physical pain Lara also described an incident when there was a physical reminder of the accidents that she had:

“And the poo...stained the carpet.” (166)

Another area in which Lara expressed negative consequences of toilet training was during her initial attempt to use the toilet. At this time she had a fantasy about what would happen:

“ I thought...I would hold on to the handle and flush myself down the toilet.”

(113)

Lara reported feeling that there were negative consequences of achieving toilet training, in particular she remembers receiving less physical contact with her mother:

“Well I didn’t use the potty so I didn’t have a lot of attention from my mum
(78)...She used to cuddle me...and say “it’s OK and...make you feel good.”
(87)

“Well sometimes when I go in my bed and my mum feels too tired so I sleep
in mum’s bed.” (436)

There were, however, positive consequences for Lara when she achieved some task associated with toilet training:

“Well. I didn’t have to ask my mum to put them back on...They’re like
knickers; you just pull them down and pull them back up.” (614)

“Well sometimes I may...be able to change my own bed and get myself
sorted.” (319)

Theme 4 – Social Consequences

Lara's feelings may have been moderated by the comparisons that she was making with her siblings and her peers. However, the impact of the social consequences on Lara was clearly buffered by the secure attachment that she had with her mother:

“I felt like a grown up because I didn't need to use the potty, I'd used the toilet...everyone else did.” (45)

Lara also had a great need for acceptance when she had an accident, the consequences of which were negative for her when she expected all people to respond in the way that her parents had responded when she had an accident. The following quote illustrates an occasion when she shared an accident experience with her siblings, which may have further moderated her developing self-image:

“The only reason I told them was that I felt that they would...say, “it's OK Lara”, but they didn't...They said, I can't actually remember but it wasn't a very nice thing.” (423)

Lara did seem concerned about the responses of her peers and other family members. This may have been a result of the reactions that she received from her siblings:

Interviewer: “I think sometimes when children have accidents as they’re getting a bit older, they worry when they go to stay with friends?”

Lara: “Yeah.”

Interviewer: “That they might have an accident.”

Lara: “Oh, I do get scared then.” (343)...

...Interviewer: “So does that stop you from seeing friends or not?”

Lara: “It did when I was younger.” (347)

“When I was about 5...I weed in my bed and I asked my Nana if she would change my bed...and, I felt as though she was being cross with me. So I ran downstairs and hid...under a blanket...cos I was upset.” (648)

Another long-term effect of having repeated accidents was the fear that she would be bullied. Although it was not clear from the interview if Lara was referring to her own fear or that of someone close to her, she did view it as a possible long-term difficulty with having bowel or bladder accidents:

Interviewer: “And how do people react when you have an accident?”

Lara: “Well sometimes they get scared I’m going to get bullied and I feel embarrassed.” (374)

Theme 5 – Emotional Consequences

Lara presented both positive and negative emotional responses to her experiences. She demonstrated embarrassment, shame and panic. Whilst these were apparent, Lara also used humour, which may have been a possible coping skill that she used to reflect on her toilet training experience as a whole:

“Well when you feel as though you don’t know what to do you feel a little bit scared.” (288)

“I felt very embarrassed and I don’t know what to do about it.” (368)

“And sometimes they used to laugh at me...and I didn’t like that.” (414)

“I was covered in poo, so I had to have a shower in the middle of the night.”
(163)

“Yeah. I cried.” (188)

“Well when I looked I ran upstairs and told my mum.” (213)

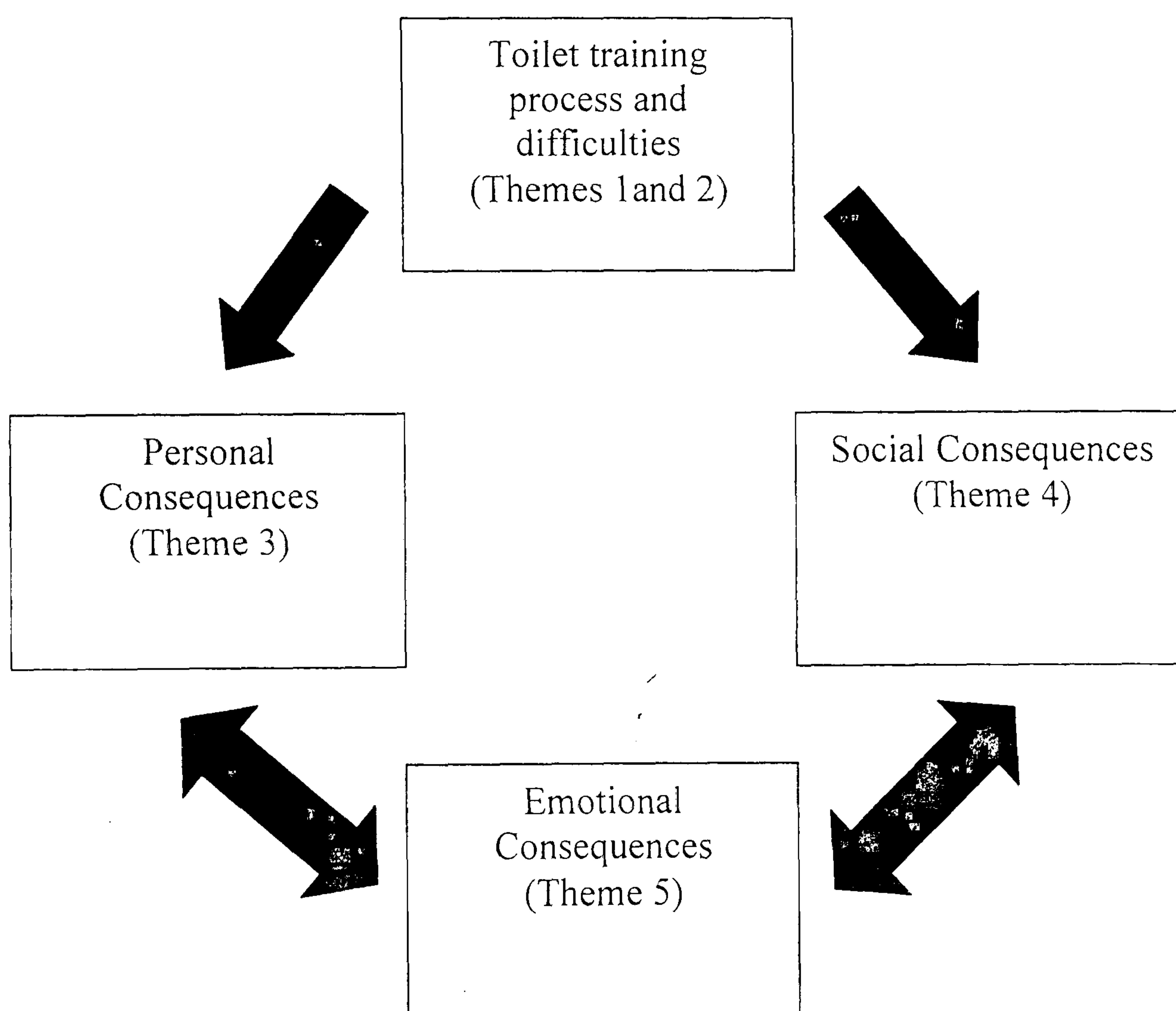
Finally Lara was able to talk about aspects of the process that were positive for her:

“It was quite an experience because I’d never actually used the toilet before...I found/the first time I used it, it was quite fun.” (40)

CONCEPTUALISATION OF LARA’S EXPERIENCES

Figure 2 has been developed to visually represent a possible relationship between the themes that emerged from the analysis of Lara’s interview.

Figure 2 – Conceptualisation of Lara’s toilet training experience



As can be seen from Figure 2, Lara's experience begins with the types of problems that she had during the toilet training process (theme 1). Depending on the techniques that are then used to address toilet training (theme 2) and the difficulties associated with these, there are either personal consequences (theme 3) or social consequences (theme 4). Both of these consequences then lead to emotional consequences (theme 5). The emotional consequences then feed back into the personal and social consequences.

DISCUSSION

The findings from Lara's interview reflect the subjective positive and negative impact that toilet training has on a child with Asperger's syndrome. Lara developed toilet training skills at the later end of the normal range, which is in keeping with the developmental delays reported in children with ASD (Wheeler, 1998; William et al., 2004). Late achievement of toilet training may impact on the treatment these children receive from staff within the educational setting. Parental reports in Summerhill et al. (2005) highlight the exclusion and the pressure that is placed upon parents and children to achieve this task in order to enter education. Again Summerhill et al. (2005) suggest that this can impact on the interaction between parent and child.

This interview has confirmed the importance of families in the experience of toilet training. Lara had a twin sibling, which may have facilitated her ability to make

social comparisons; being physically similar to her twin but having noticeable developmental differences. Her recall of earlier avoidance as a result of fear of having an accident may also have been linked to the reactions that she had experienced when reporting her accidents to her siblings at home. Research has demonstrated that teasing from siblings has a positive effect on treatment outcome (Butler et al., 1990). This may be because children are made aware of social reactions to toilet training difficulties and this may increase motivation to achieve toilet training to avoid future social ridicule. This may be due to increased sensitivity to the social reactions to these difficulties.

Lara's parents also created a positive experience of toilet training, particularly when there were difficulties. In fact, because of the bond that she had with her mother, Lara was able to reflect on the disadvantages of losing physical contact with her mother when becoming independently toilet trained. This demonstrates the importance of examining the constructions that a child has of becoming dry (Butler et al., 1990). This reflects the Enuresis literature, which suggests that parental reactions to accidents may impact significantly on the child (Butler et al., 1986; Barton & Schmitt, 1987; Butler et al., 1993; Butler, 1998). This literature highlights how parental intolerance can lead to withdrawal from treatment. Lara's parents were committed to supporting Lara in developing her independence and were able to contain and support her. They were also able to seek professional support when Lara developed secondary nocturnal Enuresis. In keeping with the literature about the

psychosocial impact of Enuresis, Lara does not appear to be psychologically disturbed (Butler, 2001) as a result of her problems with toilet training.

There are a number of limitations to this study. First it is a single case design using a qualitative methodology. It would be useful to complete this research with children who are at different levels of functioning and have different family dynamics. This is because it is an unresearched area and results from this study could be built upon, developing a greater knowledge of the important variables involved in this process. It would also be beneficial to determine gender effects on the dyads of father and son and mother and son when attempting the toilet training task.

Whilst Smith (2004) suggests that interview questions can be adjusted to meet the abilities of the populations being interviewed, this development of the IPA model is in it's infancy and further research needs to be completed. There are particular questions posed by using this methodology with a child with Asperger's Syndrome. It is not clear whether the difficulties that Lara had in answering some of the questions were because of her age or were particular to her symptoms of Asperger's Syndrome. It was evident during the interview that Lara had some difficulties in answering the questions. In some instances this was possibly due to not understanding the language used to frame the questions. It was also difficult to determine who and when Lara was talking about when she was responding to some

questions. When recalling information it was sometimes fragmented, or Lara would shift her focus from one moment in time to another moment in time.

Ability to recall information has been confounded by the retrospective design of this study. It may have been possible to complete this study with a child who was experiencing prolonged difficulties and could discuss the matters without placing demands on memory recall. However, the older a child gets, the more difficult it may be for them to discuss this type of experience, because they will have formed more stable friendships and there may be considerably more social pressure to keep this type of sensitive information hidden. (Butler & McKenna, 2002). Whilst this may be the case for Lara, it is more likely, as Lara demonstrated, that there is limited embarrassment when discussing such issues with a researcher who was a stranger to her. For some of the interview Lara's mother was present in the room, which did not inhibit the responses that Lara was giving to some of the questions. This may be due to the nature of the attachment relationship that Lara has with her mother or her difficulties associated with having a diagnosis of Asperger's Syndrome, for example, social naivety. This needs to be explored further by replicating this research with children of different ages, including typically developing children and children with a diagnosis of ASD. This may help to determine the factors that facilitate discussion and responses to questions of such a sensitive nature.

IMPLICATIONS FOR CLINICAL PRACTICE AND FUTURE RESEARCH

This case study has demonstrated the importance of considering the impact that toilet training may have upon the child. It may be possible that future research could consider including information in general toilet training books for the consideration of children with developmental and learning difficulties.

The findings here also highlight the importance of sibling relationships in learning about social reactions to toileting problems as well as for providing support. Lara appears to have benefited greatly from being in a large family with an older sibling who was present to provide support when her parents were unavailable. The importance of the mother child dyad and the normalisation and comfort provided during periods of embarrassment and shame possibly provided Lara with the insight that she had in relation to her suggestions for professionals and other families.

Not all families have the benefit of having secure attachment relationships, which further supports the need for early intervention. The literature suggests that secure attachment relationships are possible for families who have a child diagnosed with ASD (Rutgers et al., 2004). However, these relationships may be jeopardised by toilet training difficulties that are not understood within the context of having a developmental disorder.

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Chapter IV

My Reflective Journey:

“Aqua Wee (Accept Me) ”

Chapter word count (Excluding tables, figures, raw data and references): 2999

ABSTRACT

This paper illustrates the dreams that the author had during completion of the research. Dreams were recorded and analysed in order to facilitate reflection on the research process. All dreams were written in detail and were then analysed using an 'objective' method of dream analysis. Themes were developed following exploration of symbolic meanings of objects, people, places and colours in the dreams. All dreams were then given titles based on these themes and the personal meaning that the dream had for the author. Finally, messages for waking life were translated into lessons for the research, following which actions were taken to address these lessons.

INTRODUCTION TO THE REFLECTIVE JOURNEY

Pre-conceptions about the research

When I started this research journey I never believed that I would learn as much as I have. Before obtaining a place on the course I had various research posts, all of which I felt had equipped me with the skills necessary to complete this thesis. When selecting my research topic I also decided to cover a topic that I believed would be fun and not emotionally challenging i.e. something that was not personally relevant to me. I opted for exploring toilet training experiences believing it would be a 'safe' option and would not present another steep learning curve, as many things had during the course. I was hoping that completion of the research would not be de-skilling and I was excited about the opportunity of completing my own work.

Reason for dream analysis

I have always been a person who likes to reflect on the role of symbolism in my personal and professional development. I have also always been a person who can recall my dreams in great detail. Upon commencing this research I had a dream that suggested to me that there might be other subconscious reasons for my choice of topic area that I had not yet realised. Within this dream I was incontinent and initially thought it was due to participant transference issues. Following reflection on the day preceding the dream, I recalled a parent's comment about me being objective, which had possibly triggered the dream.

Upon further reflection and discussion of this dream with Delia Cushway, I believed that I was identifying with the children of the parents being interviewed because of my own childhood experience of Secondary Enuresis, which until that time I had not recalled for many years. The parent's comment about my objectivity must have triggered the realisation that I was not as objective as I initially believed I would be when reflecting on this topic.

Following the discussion with Delia Cushway I decided to keep a dream journal and to analyse these dreams. I did this to develop my understanding of the cyclical relationship between the impact that the research was having on me and the contributions I then made to the research. I also wanted to take lessons from my dreams to put into practice within the research.

DREAM RECALL

Dream recall involved waking from a dream and before rising from bed writing all of the dream that could be remembered in as much detail as possible. Recall was done at this time because the rate that dreams are forgotten throughout a day is very fast, even if the dream is very vivid (Cushway & Sewell, 1992). The dream diary was written from 14th November 2004 and is still ongoing until the paper is submitted. Dreams were written in the first person and detailed descriptions of each dream can be found in appendix P. To aid understanding of the dreams' messages I was guided through my first dream by Delia Cushway using an 'objective' method of dream recall, which is detailed in Cushway and Sewell (1992, pp 40-41). This method was used to analyse all of the dreams that

I had. How this method was applied is presented in figure 3, demonstrating the process followed, using my first dream. The dream is detailed and then the processes are outlined and demonstrated in the context of the first dream.

Figure 3: First dream recalled with description of stages of dream analysis

| | | |
|---|--------------------------------|-------------------|
| DREAM 1: | “AQUA WEE: (ACCEPT ME)” | 14.11.2004 |
| <p>I am sat inside my car, which is in a large grey concrete car park. There is open land around me with one building at the edge of the car park. The open land is green with immaculately mowed lawns. The land all around is very flat with nothing else in sight.</p> | | |
| <p>I am getting out of my car. I have a large blue gym bag on my right shoulder. I pass a red car and some other cars that do not seem to be any other colour apart from the colour of the car park itself. I don't pay much attention to the other cars. I only notice the red car because I do not like red cars. I walk straight ahead at a relaxed pace, rather than my normal faster pace and enter the building, which from the outside looks like my old nursery school. It is larger and square with just a ground floor. It also reminds me of a swimming baths that I pass when I walk through the park in K when I am awake. However, it is not green like the swimming baths that I know. It is difficult to determine a colour but I can see the bricks of the building.</p> | | |
| <p>As I enter the building I realise that it is not the gym that I usually go to so I approach the reception desk on the right to talk to the young woman that is there. She is busy</p> | | |

moving paper around so I stand and wait at the left-hand end of the desk. As I do I notice a drinks machine to the left of me that contains fizzy drinks; not water. It is blue and red like the colour of a Pepsi bottle. Apart from the colour of this machine the rest of the inside of the building is grey inside. There is a door to my right but this is only for staff so I do not take much notice of what is going on to my right. Instead I look to my left, which reveals the entrance to the gym area. The door is concealed but I know that if I were to walk behind the wall, that the entrance to the gym or changing rooms would be there. I realise this because this part of the gym is exactly the same as the swimming baths that I used to attend when I lived at home in C. However, the window, which shows the swimming area that should be in the direction that I am facing (which is to the left in front of the corridor which takes me to the entrance) is not there. Instead it is just a wall so I am now not sure if there are any baths.

The woman behind the counter is now talking on the telephone so I turn around to face the door that I came in through. Instead of walking away I stand and watch an attractive young male who I do not know, mopping the floor with an old mop with a wooden handle. The floor is white and I become aware of a strong smell of bleach, which I do not like. It is relaxing watching this person mopping. I think about talking to him but I do not move. Instead I urinate and feel my long black trousers getting wet. These are my work trousers. It feels warm and relaxing. I stand still and because no one has noticed what I have done, I urinate again. This time a pool of urine forms around my feet. I am wearing my black flat shoes that I wear to work. The urine is a pastel aqua colour. At this point the young man moves over and starts to mop up around my feet. As he does he says "can you please not do that again". I then realise what I have done and say "oh" but nothing else. I do not feel embarrassed

but instead feel annoyed that I was talked to in that way. However, I still feel calm. I start to walk in the direction of the door to leave the building and I wake up.

STAGES OF OBJECTIVE DREAM ANALYSIS

1. Recall of the dream in the first person, present tense.

This is demonstrated in the summary of the dream above.

2. Sequences in the dream are summarised substituting object and people with the word 'someone' or 'something'.

All of the dream was recalled in this way:

Someone is sat inside something, which is in something, which is large and grey.

There is something open around someone but something is on the edge. The open thing is green with something that is immaculate. Something around is very flat with nothing else in sight.

3. Identification of feelings associated with each dream sequence.

Feelings within the above dream that were noted were:

- Anger that was associated with the colour red
- Protest at being ignored
- Ambivalence with being reprimanded

- Relaxed about being in familiar surroundings associated with childhood memories.

4. Return to each action or scene noting personal meanings of people or objects, names, numbers, colours, metaphors, conflicts and resolutions.

a) Meanings of objects and people

- Gym bag = Health
- Car = Space where I can be myself
- Woman behind the counter = Bimbo/fear of lacking intellect
- Work clothes = Comfort with sharing my life energy at work/developing confidence
- Mop = Perfection
- Bleach = Dislike of perfection
- Male = Wanting to approach person for help but not knowing how to verbally ask for help
- Water in swimming baths = The support that I know is there even though I cannot quite see the entrance to it
- Pepsi bottle = Conflict between anger and calm
- Changing rooms = Ability to be myself when not at work
- Urine = Need to share my true self (life energy) with others and be accepted as I am

b) Names, words, numbers or colours

- Red = Anger/Danger/Being Noticed
- Blue = Calm/Health

c) Metaphors or puns

- Walking to gym = walking towards health
- Someone else cleaning = need for someone else to be in the caring role

d) Bizarre, paradoxical or contrasting images.

- Colour of urine was not typical colour = Life energy/acceptance of self expressing this

e) Main issues, conflicts or unresolved situations

- Difficulties expressing self at work without fear of being reprimanded or ignored

f) Positive symbols, relations or resolutions

- Support is available, I just need to ask for it
- Not ashamed of having expressed myself to others

5. Identify the major theme of the dream.

- Difficulties in expressing opinion
- Fear of being wrong and being embarrassed
- Feeling of belonging to a system that does not address clients needs effectively
- Fear of expressing disapproval within systems and appropriate ways to do this

6. Develop a title for the dream.

See top of figure 3. The title for this dream was based on the bizarre colour of the urine and the powerful symbolic message that this had for me. It encapsulated the process of self-acceptance, which paralleled the process that I believed the child that I interviewed was experiencing.

7. Message of the dream for waking life.

- Ask for support
- Develop confidence in expressing opinions within the work setting

8. Decision or action to make in waking life to actualise the dream.

- Seek support during research
- Practice expressing opinions about things. Could use the IPA consultation group as a start and then try on placement

DREAM TITLES AND THEMES

Each dream was analysed using the same process as that presented in Figure 3.

Dream titles and themes that emerged for the remaining dreams are presented in table 6.

Figure 6: Dream titles and themes

| DREAM TITLES (with dates) | DREAM THEMES |
|---|--|
| Being chased 2.2.05 | <ul style="list-style-type: none">• Wanting someone to demonstrate that they care• Not being assertive with children• No time to relax• Fear of impact that research will have on me personally |
| Need for space 8.2.05 | <ul style="list-style-type: none">• Dislike of clutter and house sharing• Need for own space• Need to not be dependent on others for help |
| Acceptance of change and disruption 8.2.05 | <ul style="list-style-type: none">• Need to be somewhere else where there is beauty and tranquillity• No need to struggle with change• OK to give up and accept what happens rather than trying to change it |

| DREAM TITLES (with dates) | DREAM THEMES |
|--|--|
| A new start 16.2.05 | <ul style="list-style-type: none"> • Debating whether to move in with partner • Need to overcome fears of moving in with partner so that plans for the future can be met |
| Chaos/fear of madness 24.2.05 | <ul style="list-style-type: none"> • Survival: thirst, hunger, need for air • Mind-body disconnection • Fear of career development • Fear for mental health decline in the future |
| Rescuer 24.03.05 | <ul style="list-style-type: none"> • Fear of not being ready for career development • Learning from previous experience/developing confidence for dealing with child protection • Developing assertiveness with work colleagues |
| Fear of rejection 26.3.05 | <ul style="list-style-type: none"> • Pushing friends away • Loneliness • Need to communicate true feelings to people |
| Self- preservation 26.3.05 | <ul style="list-style-type: none"> • Fear of not being able to cope with helping people • Need to protect myself rather than put other people first • Working through guilt of not being able to help some people |

| DREAM TITLES (with dates) | DREAM THEMES |
|---|--|
| Assertiveness 26.3.05 | <ul style="list-style-type: none">• Fear of failure• Fear of falling apart in front of people• Fear of how other people see me• Protesting being disregarded• Considering avoidance rather than challenging my phobias• Joining colleagues to work up the career ladder• Importance of support and comfort from home• Fear of being reprimanded at work |
| Feeling small and vulnerable 7.4.05 | <ul style="list-style-type: none">• Fear of doing things wrong• Inviting friends into my life• Fear of letting friends into my life• Fear of everything blowing up in my face (all progress being lost) |
| Exploding head 7.4.05 | <ul style="list-style-type: none">• Fear of loss of freedom• Help from others can be damaging to independence• Fear of impact that work is having on not being able to have the home life that I want |

LESSONS FOR THE RESEARCH

Following analysis of the dreams, where possible the dream messages as well as decisions and or actions for waking life were transformed into lessons for the research. The lessons for the research from each dream are presented in the context of daily reflections that preceded the dreams that I had.

Dream 1

Aqua Wee: (Accept me)

In the first few days preceding the first dream, I was interviewing parents and having numerous insights during the day. I identified a parallel process of constructions I had of parenthood and parent's beliefs about their roles and responsibilities. Listening to parents' stories increased my own fear of having children, given the pressures and demands placed on parents. This insight allowed me to be less judgmental of parents than I was when I started the research.

One parent reported that it is acceptable not to start toilet training early and that statistics can be used to normalise late achievement. These comments highlighted for me areas for improvement in service delivery and increased my enthusiasm for disseminating information about the improvement of services to meet the needs of the whole family.

Another parent also suggested that an important role for a parent is to accept difficulties they are having with toilet training their child and to share these with

others in order to break social taboos. I believe that professionals have a role to play in breaking this taboo by normalising the parent and child experience and disseminating this information.

Finally I had a conversation with one mother who was also conducting research in the field of Autism. She believed I would be more objective conducting research in this field because I was not a parent of a child with this diagnosis. Following these daily reflections I had my first dream, the lessons presented to me being:

- Even when investigating the same phenomena with all mothers, each experience is individual so I will use an ideographic approach rather than using the coding framework from the first transcript analysis to analyse following transcripts.
- ‘Late’ achievement is a culturally constructed term based on the demands of nurseries and primary schools for children to be toilet trained.
- A model of parents’ experiences may include impact on attachment and social identity theory.
- As a professional I have a role in increasing awareness of the degree of the toilet training problem for children diagnosed with Autism Spectrum Disorder.
- I need to be aware of my own projections when analysing the child interview transcript.
- I need to develop confidence in expressing opinions within a professional context.

Dream 2

Being chased

This dream occurred on the evening of the day when I completed my interview with the child with Asperger's Syndrome. The themes in this dream made me realise that I now had a fear that the research would become too emotionally involving and would impact on me in a personal way. The lesson for the research was:

- Important not to have a conversation with my mother regarding her recall of my Secondary Enuresis when I was 8 years old. I was already aware that this problem occurred when I moved home, just like the child I had interviewed. At this point I did not want to develop my knowledge of my own personal experience, which might interfere with the analysis of the child interview transcript. It was important to me that this research reflected the experience of the child I had interviewed.

Dream 3

Need for space

This dream occurred following reflections during the day concerning having limited time to concentrate on my relationship with my boyfriend whilst completing my work. I had become dependant upon him to complete my housework and do all of the cooking when we were together, for which I felt guilty. Although this dream did not appear to have direct lessons for the

research, there were clear symbols and messages suggestive of the following things:

- Becoming dependent upon others during completion of the research is essential.
- Starting to do this now may help me to be able to do it more easily in the future, developing my self - care, which will be important throughout my career.

Dream 4

Acceptance of change and disruption

This dream occurred in the same night, reflecting the lessons that had been taken on board from the first dream. It was almost as if I was being presented with the present and the future. This dream demonstrated to me some lessons that I had learnt since childhood (skateboard representing what I liked to do as a child), things will always change and it may not be easy but “every cloud has a silver lining”. At this point the research pressure was starting to build and I was concerned that I would lose everything that I had been working towards for so many years. There were lots of symbols of re-growth (moss and baby monkey). This demonstrated to me the following things for the research:

- The research will not last forever.
- It is another step towards being qualified, of which I am nervous about in waking life, but the monkey’s words in the dream gave me the clear message

to accept disruption and change, instead of fighting it. A very clear message for periods of time when in waking state I would engage in other activities rather than complete research tasks.

Dream 5

A new start

A couple of days before this dream I discussed moving in with my boyfriend. The benefits of doing this whilst completing the research outweighed the costs. This dream represented my two disputing halves with regards to whether to make the move or not. At the end of the dream I was actually packing my suitcase, which I believe was a very clear message that my personal relationship needed to take priority at that point in time.

Dream 6

Chaos/fear of madness

As stress was building I had this vivid and quite disturbing dream. There were many symbols and themes present. I believe that my 'survival' during the research was being questioned and was symbolised with water, oxygen, a feeding bottle, drink and food. Much like previous dreams, there was a blonde person in the dream representing my fear of lack of knowledge and also my skills working with mothers and their children. There was a real sense of helplessness in this dream, which was a reflection of how I was feeling in the waking state when contemplating the angle to take and literature to use when writing my research papers. The lessons for the research from this dream were:

- My role is not to provide the advice and support for the parents that I am interviewing.
- My role is to disseminate information regarding the provision of appropriate services for parents who are toilet training children with a diagnosis of Autism Spectrum Disorder.

Dream 7

Rescuer

In this dream there was a sense of feeling trapped yet being able to escape. The dream also contained the story of a child that I worked with whilst on my child placement, for whom there was a child protection issue that was not resolved in a way in which I had hoped for. In this dream I acted very differently. This part of the dream had the following lesson for the research:

- I can have the feeling of wanting to rescue people but I do not have to act upon it. This research is not a mercy mission. Although there are genuine problems that parents experience when toilet training their child, there is only so much that I can do.

Dream 8

Fear of rejection

I had this dream following one of the Interpretative Phenomenological Analysis (IPA) consultation group meetings, which I believe was a reaction to a disagreement with one of my colleagues within this group. I had been practising one of the lessons from my first dream by sharing my opinions with others even if they were in disagreement. One of my colleagues was very stressed and I feared that I had annoyed her. This dream reflected how I would usually have dealt with conflict, which was not what I did during the day when I had this dream; instead, I telephoned my colleague to check that there were no unresolved issues. This dream was in fact a reflection of my fear of how it could have been.

Dream 9

Self-preservation

This dream followed completion of my specialist placement in family work using Personal Construct Psychology. I was reflecting on the most prominent adolescent case that I had during this placement, which resulted in me discharging her, because I could not help her. This paralleled my often helpless feelings when hearing parent's stories about their treatment by professionals.

This is a similar theme to those appearing in dreams six and seven. This dream allowed me to further understand earlier lessons; that I have to accept my own personal and professional limits when conducting research as well as in clinical practice.

Dream 10

Assertiveness

This dream reflected to me a fear of ‘falling apart’ within the work setting. This is probably the biggest fear that still needs to be worked on when the research is completed. The hairdressers represented the recent changes that I had made in waking state in order to aid my pending transition from being a trainee to becoming qualified. The dream also represented the importance of my home life to me. The lessons for the research were:

- Need to spend some quality time with my friends and family as well as completing my research.
- Need to have the confidence to voice my beliefs about the quality of my work. This lesson may prove beneficial when completing my viva!
- Important not to let work, including my research interfere with my home life. Although things are difficult at the moment it is important to discuss issues as they arise rather than let them deteriorate.
- I also need to challenge my prejudices and phobias with regards to the research that I am completing. It is not my place to make judgements about parents but to interpret their experiences in order to disseminate these experiences to the wider community.

Dream 11

Feeling small and vulnerable

This dream reflected a fear of the progress I was making with the research 'blowing up in my face'; I feared that I would not reach my goal of completing the thesis before the hand in deadline. There was a lesson reflected in this dream which reflected lessons from previous dreams:

- Have a balance between social life and research time in order to get things finished in time for the hand in date.
- Ask friends for support if it is needed.

Dream 12

Exploding head

Later in the same evening I had a second dream reflecting my difficulties with giving up my free time to complete the research. My concerns about my relationships were reflected from which immediate action was taken based on lessons from dreams 1 and 10. The actions that I took were:

- Discussion with partner about concerns and joint problem solving with regards to balancing my time during the last few weeks of completion of the research.
- Sharing my experiences with the IPA consultation group.

OVERALL REFLECTIONS ON THE DREAM ANALYSES

When initially focusing on themes that were emerging from my dreams it became apparent that there was a developmental progression to these dreams. This reflected the developmental process that the parents and child that I interviewed went through, whilst addressing toilet training. These dreams were also a microcosm of the development I had made throughout the whole course. By looking at all of these dreams together I realised that personal and professional development is an ongoing, cyclical process, whereby reflections are made and acted upon. Before having the dreams I believed that I had already addressed some of the issues presented. Following the dreams I realised that these issues were still being processed whilst I was dreaming and were demonstrating areas where further work was needed, even if in waking state I thought that these things had already been resolved.

My real beliefs, judgement and prejudices were revealed to me in dreaming, with analysis allowing me to address and move forward rather than continually denying any need for further development.

I also became aware of repeating symbols throughout my dreams, which were significant for me to interpret. Although some symbols have a cultural significance, they are also personal to the dreamer (Cushway & Sewell, 1992). Colours such as black, white and grey revealed to me just how 'black and white' I see things and the need to consider grey areas, which was very important when analysing the interview transcripts for this research. Blue and red demonstrated

my difficulties with being assertive and genuinely relaxing and pinpointing how I could obtain a relaxed state more often than I do at present. Transport and being at stations reflected my avoidance and feelings of being ‘stuck’ with my interpretations of the transcripts and forming a conceptualisation of the parents’ experiences. Water in its different forms suggested support, loss and calm. Cats represented vulnerability, strength, aggression and gentleness; all aspects of myself during different stages of completion of the research.

Completing these dream analyses has been more revealing to me than any other reflective tool that I have experimented with to date. They have acted as ‘truth’ devices, presenting me with the things I wouldn’t like to admit to myself in waking state. Beliefs and assumptions were revealed about my research and vice versa, providing further areas for exploration within the research and self-care and parallel processes to consider whilst completing the research.

I never believed that having that first dream would have led to further insights proving useful for completion of my research. The dreams also presented lessons to put into practice before qualifying, to decrease some of my concerns about this next transition to occur in my life. I would definitely say that this reflective approach has helped me personally and professionally, both of which impact upon each other, particularly during completion of a thesis!

REFERENCES

Cushway, D. & Sewell, R (1992) *Counselling with Dreams and Nightmares*.
London: Sage Publications.

APPENDIX A

Ethical Approval

STUDENT SUBMISSION TO SCHOOL RESEARCH ETHICS COMMITTEE

1. Student's name: LISA SUMMERHILL 2. Course: CLINICAL PSYCHOLOGY DOCTORATE
(BLOCK CAPITALS)

3. Title of project: EXPERIENCES OF ALL PEOPLE INVOLVED IN TOILET TRAINING INFANTS WITH AUTISTIC SPECTRUM DISORDER (PARENTS, CHILDREN AND/OR ADOLESCENTS WITH AUTISTIC SPECTRUM DISORDER AND HEALTH VISITORS)

4. Summary of the project in jargon-free language and in not more than 120 words.

Sample: 10 PARENTS OF CHILDREN WITH AUTISTIC SPECTRUM DISORDER (+10 CONTROL GROUP - NOT ASD)
10 HEALTH VISITORS WHO HAVE HAD EXPERIENCE WORKING IN THIS FIELD
1+ CHILDREN AND/OR ADOLESCENTS WHO HAVE HAD TOILET TRAINING DIFFICULTIES
Research site: AND ARE ON THE AUTISTIC SPECTRUM.

OR HOMES OF PARENTS AND HEALTH VISITORS
Design (eg experimental): QUALITATIVE

Methods of data collection:

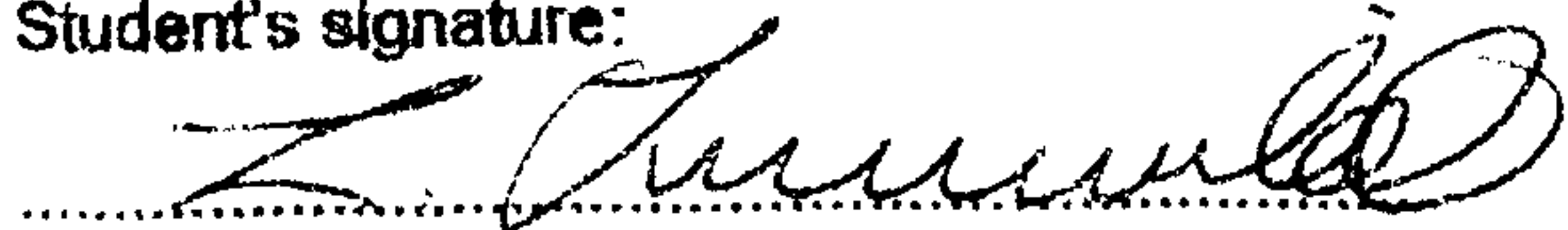
1. INTERVIEWING PARENTS AND HEALTH VISITORS REGARDING THEIR EXPERIENCES OF TOILET TRAINING INFANTS ON THE AUTISTIC SPECTRUM. ANALYSING USING QUALITATIVE CONTENT ANALYSIS.
2. GIVE PARENTS AN INFORMATION LEAFLET TO REVIEW THEN
 - a. RUN A FOCUS GROUP. -USE THEMATIC ANALYSIS
 - b. GIVE PARENTS A QUESTIONNAIRE TO COMPLETE REGARDING THE INFORMATION LEAFLET.
3. INTERVIEW AN ADOLESCENT WITH TOILET TRAINING DIFFICULTIES. ANALYSE USING INTERPRETATIVE PHENOMENOLOGICAL ANALYSIS.
4. ASK CHILDREN/ADOLESCENTS TO SEND IN THEIR STORIES ABOUT TOILET TRAINING DIFFICULTIES THAT THEY HAVE HAD. ANALYSE USING THEMATIC ANALYSIS

Access arrangements (if applicable):

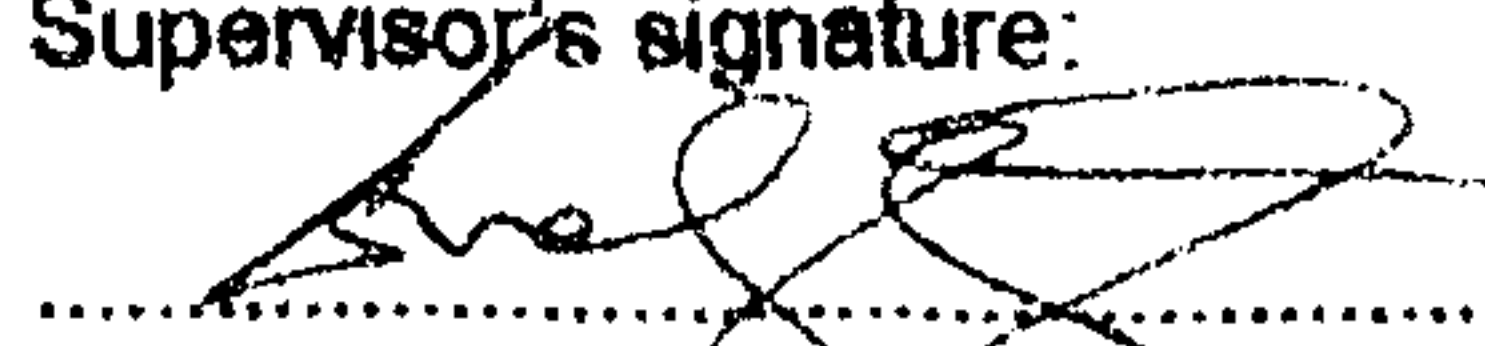
SAMPLE TO BE ACCESSED THROUGH CLINICIANS WORKING IN THE REGION
CHILDREN/ADOLESCENTS TO BE ACCESSED AS ABOVE AND FROM ADVERT ON WEBSITE FOR PEOPLE WITH THESE DIFFICULTIES.

- | | | |
|--|---|--|
| 5. Will the project involve patients(clients) and/or patient(client) data? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |
| 6. Will any invasive procedures be employed in the research? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 7. Is there a risk of physical discomfort to those taking part? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 8. Is there a risk of psychological distress to those taking part? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |
| 9. Will specific individuals or institutions (other than the University) be identifiable through data published or otherwise made available? | Yes <input type="checkbox"/> | No <input checked="" type="checkbox"/> |
| 10. Is it intended to seek informed consent from each participant (or from his or her parent or guardian)? | Yes <input checked="" type="checkbox"/> | No <input type="checkbox"/> |

Student's signature:



Supervisor's signature:



Date:

22/6/04

FOR COMMITTEE USE:

Immediate approval

☒

Referral to full School Committee

☐

Referral to local Hospital Ethics Committee

☐Decision pending receipt of further information
(specify below)☐

Committee Member's signature:

Date:



25/6/04

Text cut off in original

Local Research Ethics Committee

25 August 2004

Tel:
Fax:

Miss Lisa Summerhill
Trainee Clinical Psychologist
University of Coventry Clinical Psychology
Doctoral Course
Clinical Psychology Doctoral Course
School of Health and Social Sciences
Priory Street
CV1 5FB

Dear Miss Summerhill,

Full title of study: Experiences of all people involved in toilet training infants on the Autistic Spectrum (parents, children and adolescents with Autistic Spectrum Disorder and Health Visitors).

REC reference number: 04/Q2803/40

Protocol number: 1

Thank you for your letter of 19 August 2004, responding to the Committee's request for further information on the above research.

The further information has been considered on behalf of the Committee by the *Chairman*.

Confirmation of ethical opinion

On behalf of the Committee, I am pleased to confirm a favourable ethical opinion for the above research on the basis described in the application form, protocol and supporting documentation.

The favourable opinion applies to the following research site:

Site: _____ Trust
Principal Investigator: Miss Lisa Summerhill

Conditions of approval

The favourable opinion is given provided that you comply with the conditions set out in the attached document. You are advised to study the conditions carefully.

Approved documents

The final list of documents reviewed and approved by the Committee is as follows:

Document Type: Application
Version: 3.0 27/05/04
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Investigator CV
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Protocol
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Covering Letter
Version: 26/05/04
Dated: 26/05/2004
Date Received: 16/06/2004

Document Type: Covering Letter
Version: 19/08/04
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: Summary/Synopsis
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Peer Review
Version: 29/11/03
Dated: 29/11/2003
Date Received: 16/06/2004

Document Type: Peer Review
Version: 20/02/04
Dated: 20/02/2004
Date Received: 16/06/2004

Document Type: Compensation Arrangements
Version: 19/04/2004
Dated: 19/04/2004
Date Received: 16/06/2004

Document Type: Interview Schedules/Topic Guides
Version: Version 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Interview Schedules/Topic Guides
Version: 2
Dated: 20/08/2004
Date Received: 24/08/2004

Document Type: Copies of Advertisements
Version: 2
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: Copies of Advertisements
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Copies of Advertisements
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Letters of Invitation to Participants
Version: 1
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: Letters of Invitation to Participants
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: GP/Consultant Information Sheets
Version: 2
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: GP/Consultant Information Sheets
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Information Sheet
Version: 2
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: Participant Information Sheet
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Information Sheet
Version: 1
Dated: 27/05/2004
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Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Information Sheet
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Consent Form
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Consent Form
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Consent Form
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Consent Form
Version: 1
Dated: 27/05/2004
Date Received: 16/06/2004

Document Type: Participant Consent Form
Version: 2
Dated: 19/08/2004
Date Received: 24/08/2004

Document Type: Response to Request for Further Information
Version: 19/08/04
Dated: 19/08/2004
Date Received: 24/08/2004

Management approval

The study may not commence until final management approval has been confirmed by the organisation hosting the research.

All researchers and research collaborators who will be participating in the research must obtain management approval from the relevant host organisation before commencing any research procedures. Where a substantive contract is not held with the host organisation, it may be necessary for an honorary contract to be issued before approval for the research can be given.

Notification of other bodies

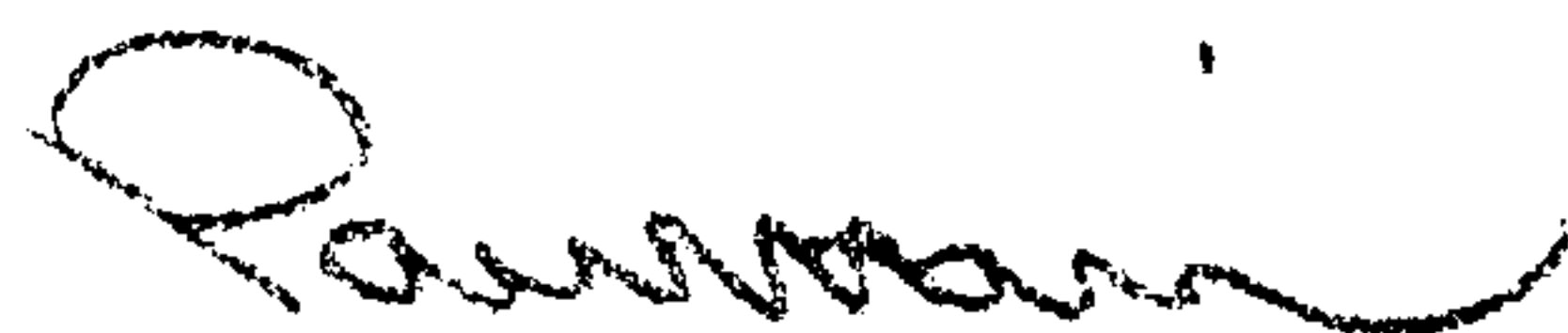
We shall notify the research sponsor,

Statement of compliance (from 1 May 2004)

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees (July 2001) and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

REC reference number: 04/Q2803/40 Please quote this number on all correspondence

Yours sincerely,



Paul Hamilton
Chairman

Enclosures Standard approval conditioner SL-AC2

c.c.

Local Research Ethics Committee

17th January 2005

Tel:
Fax:

Lisa Summerhill,
Trainee Clinical Psychologist,

Dear Lisa,

Study title: *Experience of all people involved in toilet training infants on the Autistic Spectrum*
REC reference: 04/Q2803/40
Protocol number: 1

Amendment number: 1
Amendment date: 7th January 2005

Thank you for your letter dated 7th January 2005, notifying the Committee of the above amendment.

The amendment has been considered by the *Chairman*.

This is not considered to be this to be a "substantial amendment" as defined in the Standard Operating Procedures for Research Ethics Committees. The amendment does not therefore require ethical review by the Committee and may be implemented immediately, provided that it does not affect the management approval for the research given by the R&D Department for the relevant NHS care organisation.

We have no objection to the amendment proposed in your letter as you have discussed very well the sensitivities of this subject in your paperwork and at the meeting with the Committee.

I note that you are consulting your Academic Supervisor and trust that this amendment does not undermine the scientific value of the study.

Documents received

The documents received were as follows:

Covering letter 07/01/2005
Consent Form V1 07/01/2005
Interview questions for child

APPENDIX B

Submission Instructions for Authors

Journal of Autism and Developmental Disorders

1. **Online Manuscript Submission.** Springer now offers authors, editors and reviewers of *Journal of Autism and Developmental Disorders* the option of using our fully web-enabled online manuscript submission and review system. To keep the review time as short as possible (no postal delays!), we encourage authors to submit manuscripts online to the journals editorial office. Our online manuscript submission and review system offers authors the option to track the progress of the review process of manuscripts in real time. Manuscripts should be submitted to: <http://jadd.edmgr.com>. The online manuscript submission and review system for *Journal of Autism and Developmental Disorders* offers easy and straightforward log-in and submission procedures. This system supports a wide range of submission file formats: for manuscripts — Word, WordPerfect, RTF, TXT and LaTeX; for figures — TIFF, GIF, JPEG, EPS, PPT, and Postscript.
NOTE: By using the online manuscript submission and review system, it is NOT necessary to submit the manuscript also in printout + disk. In case you encounter any difficulties in submitting your manuscript online, please get in touch with the responsible Editorial Assistant by clicking on CONTACT US from the tool bar.
2. Submission is a representation that the manuscript has not been published previously and is not currently under consideration for publication elsewhere. A statement transferring copyright from the authors (or their employers, if they hold the copyright) to Plenum Publishing Corporation will be required before the manuscript can be accepted for publication. The Editor will supply the necessary forms for this transfer. Such a written transfer of copyright, which previously was assumed to be implicit in the act of submitting a manuscript, is necessary under the U.S. Copyright Law in order for the publisher to carry through the dissemination of research results and reviews as widely and effectively as possible.
3. Type double-spaced, and submit the original and three copies (including copies of all illustrations and tables). Academic affiliations of all authors and the full mailing address of the one author who will review the proofs should be included. Unless a self-addressed stamped envelope is enclosed, manuscripts cannot be returned.
4. A 120-word abstract is to be provided.
5. Tables should be numbered and referred to by number in the text. Each table should be typed on a separate sheet of paper and should have a descriptive title.
6. Illustrations (photographs, drawings, diagrams, and charts) are to be numbered in one consecutive series of arabic numerals. Photographs should be large, glossy prints, showing high contrast. Drawings should be prepared with india ink. Either the original drawings or good-quality photographic prints are acceptable. Identify figures on the back with author's name and number of the illustration. Each figure should have an accompanying caption. The list of captions for illustrations should be typed on a separate sheet of paper. Electronic artwork submitted on disk should be in the TIFF or EPS format (1200 dpi for line and 300 dpi for half-tones and gray-scale art). Color art should be in the CYMK color space. Artwork should be on a separate disk from the text, and hard copy *must* accompany the disk.
7. The 1994 fourth edition of the *Publication Manual* of the American Psychological Association should be used as the style guide for the preparation of manuscripts, particularly with respect to such matters as the citing of references and the use of abbreviations, numbers, and symbols. We will be unable to review manuscripts that are not prepared according to these guidelines.

8. After a manuscript has been accepted for publication and after all revisions have been incorporated, manuscripts should be submitted to the Editor's Office as hard copy accompanied by electronic files on disk. Label the disk with identifying information – software, journal name, and first author's last name. **The disk *must* be the one from which the accompanying manuscript (finalized version) was printed out.** The Editor's Office cannot accept a disk without its accompanying, matching hard-copy manuscript.
9. **The journal makes no page charges.** Reprints are available to authors, and order forms with the current price schedule are sent with proofs.
10. **Springer Open Choice.** In addition to the normal publication process (whereby an article is submitted to the journal and access to that article is granted to customers who have purchased a subscription), Springer now provides an alternative publishing option: Springer Open Choice. A Springer Open Choice article receives all the benefits of a regular subscription-based article, but in addition is made available publicly through Springer's online platform SpringerLink. To publish via Springer Open Choice, upon acceptance please visit www.springeronline.com/openchoice to complete the relevant order form and provide the required payment information. Payment must be received in full before publication or articles will publish as regular subscription-model articles. We regret that Springer Open Choice cannot be ordered for published articles.

Autism: The International Journal of Research and Practice

Published in Association with:

The National Autistic Society

Editors Patricia Howlin St George's Hospital Medical School, London, UK

Rita Jordan University of Birmingham, UK

Corresponding Editor for North America Mohammad Ghaziuddin University of Michigan Medical Center, Ann Arbor, USA

Manuscript Submission Guidelines:

1. The aim of the journal is to publish original research or original contributions to the existing literature on autism. Papers should not previously have been published or be under consideration elsewhere.
2. Each paper submitted will be refereed by at least two anonymous referees.
3. Length of papers. The number of high quality submissions to the Journal has increased significantly over the last year and in order to facilitate more rapid publication of important papers it has become necessary to limit the size of manuscripts accepted. The maximum text length, therefore, should be 5000 words and the total length of the manuscript should not exceed 20 pages (double-size, 12 font, including figures and references etc.). In exceptional circumstances we may be able to accept manuscripts that exceed this length, but this should be discussed with one of the editors before submission.
4. When submitting papers for consideration, please supply four paper copies. If the paper is accepted for publication, then a copy of the final version will be required on disk. The author is responsible for guaranteeing that the final hard copy and diskette versions of the manuscript are identical.
5. In order to protect the identity of clients or participants, authors should use pseudonyms and remove any information leading to identification of any of the individuals described in the study.
6. The Editors welcome contributions to the Letters to the Editors section of the journal. In the interests of saving space, or to protect confidentiality, for example, the Editors may edit letters for publication.
7. Unsolicited manuscripts will not be returned to authors if rejected.
8. Blind peer review. Authors should provide two title pages, one containing names, affiliations, full mailing address plus telephone, fax, email address, and one containing the title only.
9. Please number all pages except the title pages, in the following order: abstract (100-150 words), keywords (up to five), address for correspondence; main text; appendices; acknowledgements; notes; references; tables; figure captions; figures. Each of the above sections should start on a fresh page.
10. Articles submitted for publication must be typed (or word processed) in double spacing throughout (especially all notes and references), on one side only of white A4 or US standard paper, with generous left- and right-hand margins but without justification.

Pages should not be stapled. Titles and section headings should be clear and brief with a maximum of three orders of heading.

11. Quotations. Lengthy quotations (exceeding 40 words) should be displayed and indented in the text.

12. American or UK spelling may be used, to the author's preference. Indicate italics by underlining and use single quotation marks. Dates should be in the form '9 May 1995'. Delete points from 'USA' and other such abbreviations.

13. Tables and figures should have short, descriptive titles, and be clearly numbered. All footnotes to tables and their source(s) should be typed below the tables. Column headings should clearly define the data presented. Camera-ready artwork must be supplied for all figures. The location of tables and figures in the text should be given by a note 'Table/Figure X about here' on a separate line in the text.

14. References in the text should be presented in the Harvard system, i.e. the author's name and year of publication in brackets, together with the page number, e.g. 'As Hobson (1989, pp. 22–3) has observed...', or, in a more general reference:

'Scott (1985) appears to be saying that...'.
 ...

15. Reference list. The references should be listed alphabetically in full at the end of the paper, typed double-spaced for ease of editing, in the following style:

Happé, F. (1995) *Autism: An Introduction to Psychological Theory*. Cambridge, MA: Harvard University Press.

Hobson, R.P. (1989) 'Beyond Cognition: A Theory of Autism', in G. Dawson (ed.) *Autism: Nature, Diagnosis and Treatment*, pp. 22-8. New York: Guilford.

Sigman, M.D., Kasari, C., Kwon, J. & Yirmiya, N. (1992) 'Responses to the Negative Emotions of Others by Autistic, Mentally Retarded and Normal Children', *Child Development* 63(3): 796-807.

In multi-authored articles, the names of all authors should be given in the reference list. In the text, if there are more than two names, please give the first name and et al.

NB: (eds) as a contraction but (ed.) as an abbreviation.

16. Language and terminology. Jargon or unnecessary technical language should be avoided as should the use of abbreviations (such as coded names for conditions). Please avoid the use of nouns as verbs (e.g. to access), and the use of adjectives as nouns (e.g. autistics, normals or retardates). Wherever possible use phrases such as 'children with autism' rather than 'autistic children'. Language that might be deemed sexist or racist should be avoided.

17. Abbreviations. As far as possible, please avoid the use of initials, except for terms in common use. Abbreviations that are common enough to be in the dictionary, e.g. IQ and USA, are acceptable, but AS (for Asperger syndrome) and SPS (for semantic pragmatic syndrome) are not. Please provide a list, in alphabetical order, of abbreviations used, and spell them out (with the abbreviation in brackets) the first time they are mentioned in the text.

18. Authors will receive proofs of their papers and 25 offprints of the published version, plus one copy of the printed journal.

19. Copyright. On acceptance of their paper, authors will be asked to assign copyright to Sage Publications Ltd and The National Autistic Society, subject to retaining their right to reuse the material in other publications written or edited by themselves, and due to be published preferably at least one year after initial publication in the journal. Authors are responsible for obtaining permission from copyright holders for reproducing any illustrations, tables, figures or lengthy quotations previously published elsewhere.

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21. Reviews. Books and suggestions should be sent to the Reviews Editor: Tony Charman, The Behavioural Sciences Unit, Institute of Child Health, 30 Guilford Street, London WC1N 1EH. Email: t.charman@ich.ucl.ac.uk

22. Covering letter. Please attach to every submission a letter confirming that all authors have agreed to the submission and that the article is not currently being considered for publication by any other print or electronic journal.

Dreaming

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Manuscripts will be reviewed by editors and referees in the author's field. Manuscripts should be checked for content and style (correct spelling, punctuation, and grammar; accuracy and consistency in the citation of figures, tables, and references; stylistic uniformity of entries in the References section; etc.), as the typesetter is instructed to follow (accepted) manuscripts as presented. Page proofs are sent to the designated author for proofreading and checking. Typographical errors are corrected; authors' alterations are not allowed.

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3. Manuscripts should be typed double-spaced in 12-point type with generous margins on all sides, and should be in APA style as outlined in the Publication Manual of the American Psychological Association (5th. ed.).

4. A title page is to be provided and should include the title of the article, author's name (with degree), author's affiliation, and suggested running head. The affiliation should consist of the department, institution (usually university or company), city, and state (or nation) and should be typed as a footnote to the author's name. The suggested running head should be fewer than 50 characters (including spaces) and should consist of the article title or an abbreviated version thereof. For office purposes, the title page should

include the complete mailing address and telephone number of the one author designated to review proofs.

5. An abstract is to be provided, preferably no longer than 120 words.

6. A list of 3–5 keywords should be provided directly below the abstract. Keywords should express the precise content of the manuscript, as they are used for indexing purposes.

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APPENDIX C: Parents' invitation letter for participation in the research

Dear

Re: Participation in a research study regarding toilet training infants on the autism spectrum

I'm writing to you about your possible participation in a local research study. This study is about the experiences of people who are involved in toilet training infants who are on the autism spectrum. This will involve interviewing parents about their experiences.

Please find enclosed an information leaflet regarding this study and a consent form. Please read the information leaflet and if you're interested in participating, sign the consent form. A stamped addressed envelope has been included with this letter for return of the form. If you do not wish to take part in the research, you only have to return the consent form if you want to and this will not affect your involvement with our service at all in the future.

If you have any queries regarding the information enclosed or the study itself please feel free to call me on the above telephone number.

Yours sincerely

(Clinician)

APPENDIX D:
Information given to parents about research

Information Sheet

Toilet training infants on the autism spectrum

You are being invited to take part in a research study. Before you decide if you want to participate in this study, it is important for you to understand the reasons for this research and what you will be required to do.

Please read the following information carefully and discuss it with others if you wish to do so. If anything is not clear please feel free to contact us for further information. Please take as much time as you need to decide whether or not you wish to take part in this study.

Thank you for taking the time to read this.

Purpose of the study

There is much research in the field of toilet training infants. This research has led to sharing of information between parents and Health Visitors regarding the best practices for toilet training an infant. Literature in the field of toilet training infants that have other difficulties such as those associated with a child being on the autism spectrum is limited. Although there are single case reports of the types of difficulties that parents have when toilet training their infants who are on the autism spectrum, personal experiences and implications of these difficulties have not been explored.

The purpose of this study is to explore toilet training experiences of parents of children who are on the autism spectrum. It is hoped that this will be done by interviewing parents as well as gathering information from a child who has experienced difficulties with toilet training. After completion of all interviews the second aim of the study is to develop an information leaflet that can be given to parents of children on the autism spectrum in the future, should they have similar difficulties.

Why have you been approached?

If you are a parent who has a child on the autism spectrum (having received a clinical diagnosis following an assessment completed by more than one professional) you have been approached for this research. All children of parents being interviewed will be aged between 4-8 years of age. None of the children of parents being interviewed will have significant general learning disabilities or physical impairments.

It is hoped that a total of 10 parents will be interviewed (including both mothers and fathers).

Do you have to take part?

It is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and be asked to sign a consent form. If you decide to take part you are still free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of care you receive in the future.

Who is organising the study?

This study is being organised both by Coventry University Clinical Psychology Doctoral Course and **** (NHS Trust). Funding for this study as well as Clinical and Academic Support for the Research is provided by Coventry University.

Clinical support is being provided by NAME OF CLINICIAN (Senior Clinical Medical Officer) and NAME OF CLINICIAN (Consultant Clinical Psychologist). Academic support is being provided by Dr Eve Knight (Clinical Psychologist).

LREC approval

The Local Regional Ethics Committee has given approval for this study. For this region it is the **** (region) Local Research Ethics Committee.

What will happen to you if you take part in the study?

If you agree to take part in this research you will be interviewed on one occasion by Lisa Summerhill (Trainee Clinical Psychologist). You will be interviewed in the place that is most convenient to yourself. This will most likely be in your own home or you can come to the **** (clinic) or the **** (clinic).

Interviews are expected to last no longer than 60 minutes and will be tape-recorded. When the interview has been completed the investigator will type up what was said during the whole interview. You will then be sent a copy of the script of the interview to check accuracy and for information to be withdrawn from the script should you wish.

Information will be used with all other interview scripts to form an understanding of experiences of parents toilet training infants who are on the autism spectrum.

Disadvantages to taking part in the study

The only disadvantages that might occur as a result of taking part in this study is the possible emotional impact of talking about this sensitive area and the implications for some children and their families as a result of having difficult toilet training experiences. If this should occur it has been agreed that you can contact the clinician that works with you and your child to discuss the impact. If you are not in contact with a clinician please feel free to contact Lisa Summerhill (contact details at the end of this information sheet).

Benefits of taking part in the study

We do not anticipate any benefit to yourself but it may be beneficial to future parents accessing services for support when toilet training their infant.

Confidentiality

All information about you will be kept strictly confidential. Any information about you that is not kept within a hospital site will be made anonymous so that you cannot be recognised from it.

Tapes of the interviews will be securely stored and destroyed at the end of the project (after publications have been completed).

However, if during the course of the research it is revealed that you may be a risk to yourself or to other people, it will be necessary to contact other professionals/services to inform them of this risk. If this needs to be done this will be discussed with you first.

What if new information becomes available?

Sometimes during the course of a research project, new information becomes available about the topic being studied. If this happens, your research contact will tell you about it and discuss with you whether you want to continue in the study. If you decide to withdraw, your research contact will make sure that this will not affect your future treatment by services. If you decide to continue in the study you will be asked to sign an updated consent form.

Also, on receiving new information your research contact might consider it to be in your best interests to withdraw you from the study. They will explain the reasons for this to you.

What if something goes wrong?

If you feel you are harmed by taking part in this research, there are no special compensation arrangements. If you are harmed due to someone's negligence, then you may have grounds for a legal action but you may have to pay for it. Regardless of this, if you wish to complain, or have any concerns about any aspect of the way you have been approached or treated during the course of this study, the normal National Health Service complaints mechanisms is available to you.

What will happen to the results of the study?

Results of the study will be written up as research papers for a research thesis as part of the Clinical Psychology Doctoral Course. These papers may be submitted for publication in national journals that are relevant to the topic area covered.

No-one taking part in the study will be identifiable in the write up of the research. If you require a copy of the results submitted for publication please feel free to request this and a summary of the results will be given to you. If the research is published you will also be informed of where it has been published and how you can obtain a copy of the publication.

Contact for further information

For further information please feel free to contact:

Lisa Summerhill
Trainee Clinical Psychologist
Clinical Psychology Doctoral Course
School of Health and Social Sciences
University of Coventry
Priory Street
Coventry
CV1 5FB

Telephone: 024 7688 8328

(CLINICIAN CONTACT DETAILS)

If you would like to explore this further with someone independent of the research please feel free to contact anyone whom you feel may be appropriate.

After reading this information, please complete the consent form overleaf. You will be given a copy of this information sheet form to keep. Once again I would like to thank you for taking the time to read this information.

APPENDIX E: Consent form for parents

Study number:
Participant information number:

CONSENT FORM

Title of study: Toilet training infants on the autism spectrum

Name of Researcher: Lisa Summerhill

Please tick the boxes that apply to you and sign your name at the bottom of the form. Thank you for your time.

1.

I confirm that I have read and understand the information sheet for the above named study.

☐
2.

I understand that my participation is voluntary and that I am free to withdraw at any time without any of my rights and treatment being affected.

☐
3.

I agree to my GP being informed that I am taking part in the study.

☐
4.

I agree to take part in the study

☐

Please write telephone number so you can be contacted

OR

☐

I do not agree to take part in the study
(if you tick this box you only have to sign and return this form if you want to)

Name of participant

Signature

Date

Witness

Signature

Date

APPENDIX F:

Semi-structured interview questions for parent interviews

1. Can you tell me in your own words what it has been/is like to toilet train your infant?
2. Can you give me details of the process that was involved in toilet training your infant. What steps did you take from starting to toilet train your infant to achieving what you were aiming for?
OR How did you go about toilet training your infant?
3. How old was your child when you first attempted to toilet train?
4. At what age did your infant develop urinary continence
OR become dry during the day and night?
5. At what age did your infant develop bowel continence
OR bowel control?
6. At what age did your child stop using nappies?
7. Were there any problems that you experienced when you attempted to toilet train your child?
8. What were these difficulties?
9. Were there any positive things that you experienced when toilet training your infant?
10. What support have you received from services or from other people in relation to toilet training your infant/ with regards to the types of difficulties that you have/have had whilst toilet training your infant?
11. What techniques have you tried that have not worked in relation to any specific problems that you have had toilet training your infant?
12. What techniques have you tried that have worked in relation to any specific problems that you have had toilet training your infant?
13. What feelings have you experienced whilst toilet training your infant?
14. Have you had any feelings that you felt were negative or difficult to cope with?
15. Have you had any positive feelings whilst toilet training your child?
16. What implications do you think that there is for a child on the autism spectrum who has toilet training difficulties?

17. What do you think professionals could do in order to help with these difficulties?

- ◆ GP
- ◆ Health Visitors
- ◆ Social Workers
- ◆ Other health professionals
- ◆ Voluntary organisations
- ◆ Support groups

18. What do you think professionals could do in order to help with these long-term implications?

- ◆ GP
- ◆ Health Visitors
- ◆ Social Workers
- ◆ Other health professionals
- ◆ Voluntary organisations
- ◆ Support groups

APPENDIX G: Table summarising the process of theme formation based on the IPA approach (adapted from Smith & Osborn, 2003)

| Stage | Stage description |
|--|--|
| 1 – Reducing of raw information | Initially an idiographic approach will be used (Smith et al. 1995). Using single interview transcripts themes will be identified and working slowly up to a more general categorisation of data. |
| 2 – Identifying themes | For each transcript the investigator will make preliminary notes. Key words will be used to capture the essential contents of the text. Abstract theme titles will then be developed. |
| 3 – Searching for connection between themes | Whilst these themes are developing, connections will be made between emerging themes throughout the whole transcript for each interview. |
| 4 – Creating a master list of themes | It may then be possible to pull together the initial categories to form superordinate themes. At each stage of theme development the investigator will examine how well the themes fit the original transcripts. A cyclical process will be used allowing for the development and changing of themes so that they remain as closely related to the original transcripts as possible. |
| 5 – Creating a table of themes | A table of themes ordered in a coherent manner will then be created. |
| 6 – Narrative account of themes | These themes will be written as a narrative account of the parental experience of toilet training children on the autism spectrum. This narrative account will include quotes from the transcripts to illustrate the themes (including participant and line number e.g. 1.111 = participant 1, line 111 in the transcript) |
| 7 - Conceptualisation of experiences | A diagrammatic representation of parents’ experiences will be created to demonstrate an understanding of how the superordinate themes possibly link in such a way to create parent’s experiences. |

APPENDIX H:

Extract from parent transcript demonstrating stage 2 of the IPA analysis

Stage 2: Key words capturing contents of the text in one interview transcript

| | |
|--|---|
| <p>OK. So it's W that we're talking about?</p> <p>We are</p> <p>Yeah. So can you tell me in your own words what it has been like to toilet train W?</p> <p>He was later than any of the others.</p> <p>Umum</p> <p>And he was completely INAUDIBLE, um, so he didn't really show any signs at all of, um (pause) even signs of particularly noticing when he was wet.</p> <p>Um</p> <p>Um. He did a bit and and and then he'd tell you. But then just/I just didn't seem able to connect with the idea that INAUDIBLE He'd watch his brother go to the loo</p> <p>Um</p> <p>And INAUDIBLE so, you know, he knew what it was for.</p> <p>Yeah</p> <p>Um, and uh and he sat on his potty and stuff. Um and he then was at nursery in the morning.</p> <p>Um</p> <p>Um. And so he was about INAUDIBLE and then we worked together and we just had to be very very explicit with him with stuff that INAUDIBLE you had to kind of, um, say much more explicitly to him that this was what was expected of him</p> <p>Um</p> <p>Um. And then in fact once, once he'd um. It seemed to click that "oh right, OK, I didn't realise that was what you wanted me to do. OK, I'll do it" and it was fine</p> | <p>Sibling comparison</p> <p>Sensory awareness</p> <p>Sibling role model</p> <p>Child centred approach</p> <p>'Clicked' – Parent's lack of control over the process</p> |
|--|---|

Stage 2: Initial list of abstract theme titles from one interview transcript

Started late
Point when problem recognised
Child attempts to get to the toilet
Parent encouraging independence
Child's resistance to change
Child tense when on the toilet
Parents feeling helpless
Child has control over bowel movements
Using the toilet a novel experience
'Sit and grunt method'
Exposure to feared activity of sitting on the toilet
Encouraging independence through social comparison
Automatic achievement of not wetting the bed
No bowel accidents
Problems associated with ASD not control/awareness
Parent's awareness of developmental stage of the child
Self-care not achieved
Cannot formally instruct a child with ASD
Awareness of child's difficulties in learning
Awareness of child's difficulties and fears
Child's role change from passive to active when learning to use the toilet
Social pressure not a motivational factor for toilet training children with ASD
Individualising rewards for sitting on the toilet works
Awareness that the child is different before receiving a diagnosis
Trying numerous methods
Potty not practical for the parent
Refusal to poo in the potty
Case histories in a book normalises poo problem
Comparison of types of problems with other parents
Comparison of age of achievement across generations
Parent acceptance of the process of toilet training
Support from partner
No specific solution
Not giving up/Persistence and patience
(Lack of) awareness of child's difficulties
Parent feeling helpless
Quick achievement of using the toilet once fear resolved
Physical awareness follows overcoming fears of using the toilet
Social implications in an academic setting
Diagnosis increases awareness of the child's difficulties
Diagnosis prepares parents for difficulties
Health Visitor not highlighting ASD
Parent directly approaching professional and querying diagnosis directly
Awareness of ASD symptoms early on
Smooth care pathway
Expectations of toilet training to be easier for child without ASD
Awareness problems could be addressed by using traditional nappies
Child uncomfortable in traditional nappies

APPENDIX I:

Table summarising where in the parent transcripts each theme appears

| <p>SUPER-ORDINATE THEME TITLE</p> | <p>APPEARANCE IN TRANSCRIPTS (LINE NUMBERS)</p> |
|--|---|
| <p>SYSTEMIC RELATIONSHIPS</p> | |
| <p>Comparison with others</p> | <p>Participant 1: 50; 129; 176; 182; 190; 202; 239 Participant 2: 10 Participant 3:165; 186; 212; 322; 333; 428; 542; 495; 575; 665; 698; 746; 909; 1037; 1110; 1174; 1245; 1270; 1311; 1469; 1565; Participant 4: 70; 95; 111; 180; 209; 278; 363; 386; 616 Participant 5: 30; 49; 134; 273; 512; 560; 595; 681; 695; 710; 730; 784; 825; 870; 1120; 1292 Participant 6: 5; 60; 75; 153; 193; 408; 690 Participant 7: 98; 381; 556; 576; 638; 658; 716 Participant 8: 149; 174; 436; 689; 789</p> |
| <p>Information Sharing</p> | <p>Participant 2: 382; 389; 458 Participant 3: 49; 65; 138; 187; 334; 364; 628; 877; 888; 906; 974; 986; 999; 1005; 1095 Participant 4: 410; 431; 445; 477; 547 Participant 5: 680; 764; 787; 1099 Participant 6: 85; 311; 523 Participant 7: 315; 667; 852; 890 Participant 8: 10; 301; 524; 554; 566; 684</p> |
| <p>Social Implications</p> | <p>Participant 1: 132; 253; 263 Participant 2: 533 Participant 3: 32; 136; 242; 272; 294; 518; 1023; 1133; 1429 Participant 4: 284; 468 Participant 5: 90; 187; 1208; 1298 Participant 6: 192; 222; 437; 461; Participant 7: 103; 193; 372; 420 Participant 8: 7; 61; 169; 503; 730; 740</p> |
| <p>Family functioning</p> | <p>Participant 1: 24; 37;83; 107; 118; 334 Participant 2: 68; 265; 278; 328 Participant 3: 120; 201; 235; 307; 394; 412; 544; 708; 892; 937; 1268; 1490; 1511 Participant 4: 56; 158; 500; 685 Participant 5: 208; 371; 584; 622; 648; 686; 701; 712; 737; 749; 1191 Participant 6: 12; 63; 346 Participant 7: 63; 108; 168; 242; 545; 576; 746; 774; 808; 910 Participant 8: 36; 209; 644; 763</p> |
| <p>Effective support</p> | <p>Participant 1: 208; 266 Participant 2: 337 Participant 3: 79; 146; 523; 534; 638; 654; 672; 685; 817; 934; 969; 1001; 1047; 1128; 1141 Participant 4: 169; 541 Participant 5: 8; 725; 740; 1218 Participant 7: 291; 843; 874; 901 Participant 8: 31</p> |

| SUPER-ORDINATE THEME TITLE | APPEARANCE IN TRANSCRIPTS (LINE NUMBERS) |
|---------------------------------------|---|
| KNOWLEDGE BASE | |
| Testing techniques | Participant 1: 63; 152; 224 Participant 2: 62; 232 Participant 3: 40; 85; 144; 378; 1282; 1337 Participant 4: 62; 73; 91; 130; 325; 336; 496 Participant 5: 27; 65; 104; 122; 153; 292; 326; 345; 427; 488; 505; 1120; 1180; 1305 Participant 6: 25; 77; 161; 171; 325; 334; 349; 374 Participant 7: 52; 110; 145; 233; 591; 689 Participant 8: 80; 90; 109; 188; 204; 273; 632 |
| Awareness of Developmental stages | Participant 1: 14; 31; 75; 119; 137; 244; 343; 358 Participant 2: 23; 120; 150; 237 Participant 3: 43; 96; 114; 192; 200; 265; 299; 306; 448; 608; 700; 942; 1269; 1353; 1397; 1409; 1435 Participant 4: 12; 193; 238; 257; 270; 576; 605 Participant 5: 14; 43; 62; 133; 149; 157; 372; 612 Participant 6: 8; 31; 235; 383 Participant 7: 5; 51; 72; 92; 205; 282; 632 Participant 8: 21; 37; 51; 96; 106; 235; 343; 378 |
| Child Centred Approaches | Participant 1: 88; 140; 337 Participant 2: 221; 262; 275; 283; 301; 321 Participant 3: 98; 224; 379; 424; 482; 644; 692; 700; 717; 880; 996; 1250; 1253; 1265; 1307; 1312; 1448 Participant 4: 198; 205; 373; 489; 524; 569; 587; 614; 622; 641; 653; 659; Participant 5: 321; 333; 341; 366; 378; 1175; 1188; Participant 6: 20; 41; 89; 106; 137; 155; 272; 332; 355; 526; 633 Participant 7: 220; 244; 247; 251; 291; 574; 726; 776 Participant 8: 74; 227; 639; 646; 683 |
| APPRAISAL | |
| Intellectualisation | Participant 3: 148; 178; 194; 279; 404; 499; 539; 757; 1031; 1208; 1314; 1383; Participant 4: 226; 416 Participant 5: 167 Participant 6: 175; 286 Participant 7: 268; 644 Participant 8: 382; 429 |
| Minimising | Participant 1: 195 Participant 3: 293; 442; 599; 674 Participant 4: 376 Participant 5: 462; 1321 Participant 6: 216; 427; 519; 525; 548; 677; 692 Participant 7: 448 Participant 8: 177; 480; 734; 755; 816 |

| SUPER-ORDINATE THEME TITLE | APPEARANCE IN TRANSCRIPTS (LINE NUMBERS) |
|---------------------------------------|--|
| Catastrophic Thinking | Participant 3: 3; 8; 103; 145; 290; 345; 743; 799; 1109; 1401; 1497; Participant 4: 135; 570 Participant 5: 576; 742; 1085 |
| Normalisation | Participant 1: 125 Participant 2: 395; 403; 442; 484 Participant 3: 237; 325; 358; 432; 571; 752; 804; 840; 979; 1386; 1398 Participant 4: 100; 311; 366; 388; 454; 648; 707 Participant 5: 75; 235; 264; 340; 398; 482; 522; 732; 883; 1107; 1164 Participant 6: 267; 585; 648; 666; 683; 707 Participant 7: 755; 855; 895 Participant 8: 507; 666; 728 |
| Accepting | Participant 1: 200; 206 Participant 3: 74; 111; 671; 1292; 1300 Participant 4: 589 Participant 5: 242; 479; 484; 509; 519; 1169; 1212 Participant 6: 242; 516; 629; 671 Participant 7: 356; 387; 411; 440; 479; 564 Participant 8: 33; 65; 140; 153; 421; 599; 784 |
| EMOTIONS | |
| . | Participant 1: 21; 27; 28; ; 110; 187; 231; 235, 246; 247 Participant 2: 134; 153; 252; 259; 265; 268; 290; 297 Participant 3: 8; 90; 93; 127; 198; 226; 231; 239; 256; 259; 290; 378; 382; 397; 402; 419; 616; 681; 796; 976; 1095; 1234; 1274; 1308; 1448 Participant 4: 196; 363 Participant 5: 54; 200; 229; 277; 501; 548; 567 Participant 6: 404; 467; 472; 703 Participant 7: 267; 279; 379; 452 Participant 8: 40; 143; 215; 412; 453; 517; 539; 708; 804 |

APPENDIX J:

Information sheet given to Lara

Information Sheet

Toilet training infants on the autism spectrum

You are being invited to take part in a research study. Before you decide if you want to take part, you need to know what you will have to do if you take part.

Please read this letter carefully and talk to your parents about it. If you have any questions please contact us at the address at the bottom of this letter.

Thank you for reading this.

Reason for doing the study

There is not much research that has been done about learning to use the toilet. The only research that has been done has reported the types of difficulties that children and their parents have when the child is being toilet trained. No research has thought about the effects that problems have on children and their parents.

This new research that we want to do will involve interviewing children and adults about toilet training. Information that we get from these interviews will be used to help doctors to help children and their parents in the future if they have difficulties with using the toilet.

Why have you been asked to take part?

You have been asked to take part in this study because you have been learning to use the toilet and have had some difficulties with this.

Do you have to take part?

You only have to take part in the research if you want to. If you say that you want to take part in the research you will be asked a few questions about your experience of learning to use the toilet.

What will happen to you if you take part in the study?

Your answers to questions that you will be asked will be taped and written down on paper. You can then see what has been written down and can ask for things to be taken out if you don't want people to know some things.

Bad things about taking part in the study

You may become upset whilst talking about what it is like for you to have the problems that you have. If this happens you can talk to your doctor about this.

Good things about taking part in the study

You will not get anything for taking part in the research. But the answers that you give to the questions in the interview will be used to help doctors to understand about problems that children have and to help doctors to help these people in the future.

Confidentiality

No one will know that you have taken part in the research apart from ***** (Clinician) and Lisa Summerhill.

The tape of the interview will be locked in a cupboard and will then be destroyed at the end of the research.

However, if during the interview we think that you may hurt yourself or other people or we think that other people are hurting you we will have to tell other people. If we do this we will tell you that we are doing this.

Contact for further information

Lisa Summerhill
Trainee Clinical Psychologist
Clinical Psychology Doctoral Course
School of Health and Social Sciences
University of Coventry
Priory Street
Coventry
CV1 5FB

After reading this information, please sign your name on the next sheet and ask one of your parents to sign it. You will be given a copy of this sheet to keep. Thank you for reading this.

APPENDIX K: Consent form for Lara

Study number:

Participant information number:

CONSENT FORM

Title of study: Toilet training

Name of Researcher: Lisa Summerhill

Please tick one of the boxes to show if you want to be interviewed or not.

5. I do not want to be interviewed

☐

OR

6. I do want to be interviewed

☐

| Name of child | Signature | Date |
|---------------|-----------|-------|
| _____ | _____ | _____ |

| Parent/s | Signature | Date |
|----------|-----------|-------|
| _____ | _____ | _____ |
| _____ | _____ | _____ |

APPENDIX L:

Semi-structured interview questions for Lara's interview

1. Can you remember what it was like when you first started to use the toilet?
2. What did you think about using the toilet?
3. What was good about using the toilet?
4. What was bad about using the toilet?
5. What was it like when you had an accident during the day?
(Explain that an accident means doing a wee or poo in pants)
6. What did mum and dad do when you had an accident during the day?
7. How did you feel when you had an accident during the day?
8. What was it like when you had an accident at night when you were in bed?
9. What did mum and dad do when you had an accident at night?
10. How did you feel when you had an accident at night?
11. Can you remember any of the things that you tried to do to help you to not have an accident?
12. What was good about these things?
13. What was bad about trying these things?
14. Did other people know about the accidents that you had during the day?
15. What did they do or say when they knew about your accidents?
16. How did that make you feel?
17. Did other people know about the accidents that you had during the night?
18. What did they do or say when they knew about your accidents?
19. How did that make you feel?
20. What do you think would have helped you not to have accidents?
21. What would you have liked other people to do when you had an accident?
22. What would make learning to use the toilet fun?
23. What makes learning to use the toilet difficult?

24. What can other people do for children who are having accidents when they are learning to use the toilet?
25. Would you like to tell me anything else about what it is like for you using the toilet or learning to use the toilet?
26. What would you say to someone who is learning to use the toilet?
27. What would you say to someone who is having accidents during the day?
28. What would you say to someone who is having accidents at night?

APPENDIX M: Thank you letter sent to Lara

Dear Lara



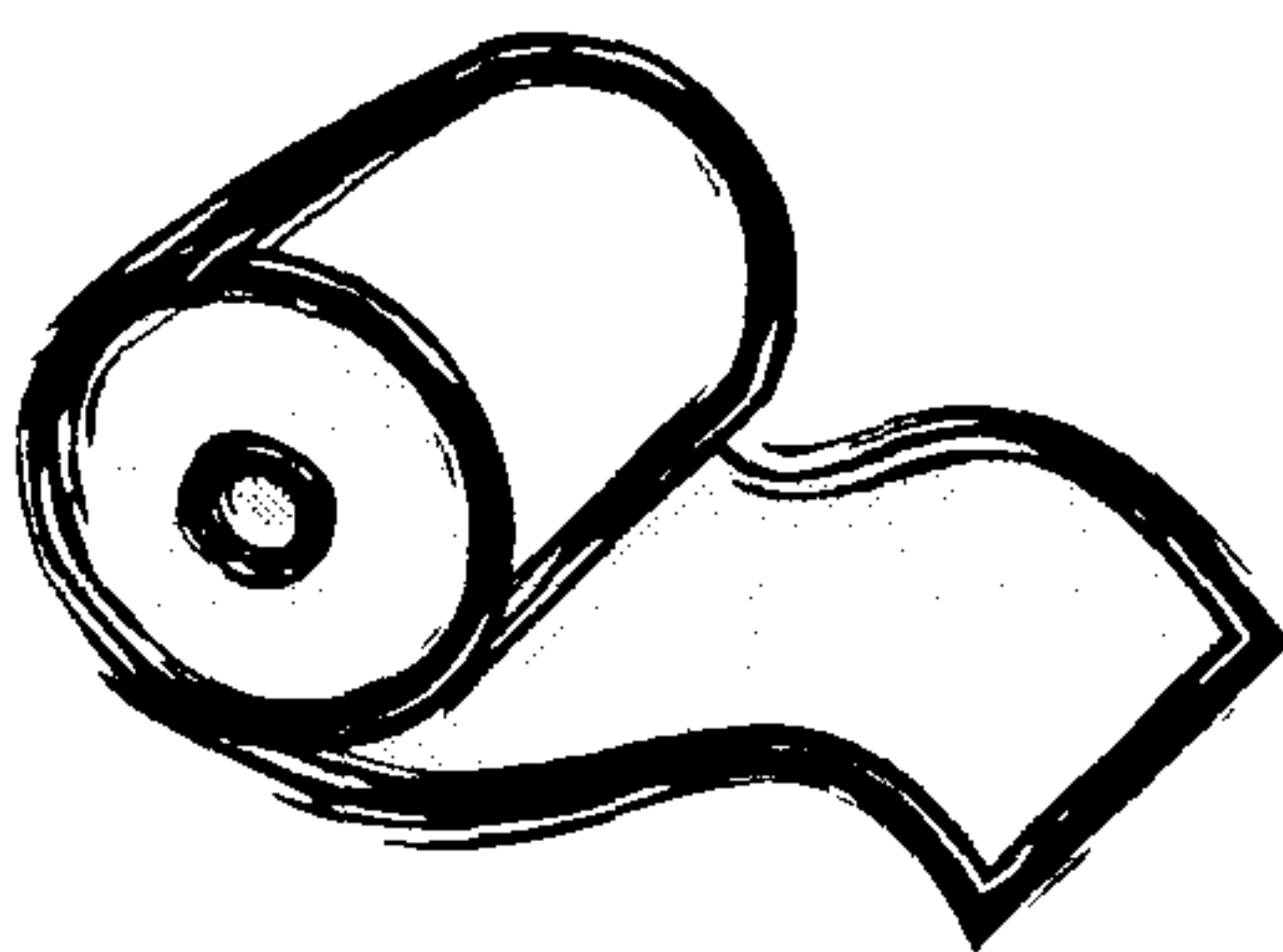
I am writing to thank you for seeing me to do the interview about your experiences of toilet training. It was very nice to meet you and to talk to you about your experience. The answers that you gave to my questions were very useful and I am looking forward to being able to write a journal article about your experiences.

I have sent you a copy of what you said to me in the interview so that you can read it. The darker writing is the questions that I asked you and the lighter writing is the answers that you gave to the questions that I asked you.

I will telephone you in a few days to ask you if it is OK to use the answers that you have given to the questions when I write the journal article. You can ask your mum for help if you need to when you are reading what I have sent to you.

When I have finished writing the journal article about your experience I will send you a copy of it so that you can see how I have used the information that you gave to me. You may want your mum to help you to read that article when I send it to you because it will have lots of words in it that your mum will be able to explain to you.

Once again, thank you very much for all of your help. I wish you all the best in the future.



Yours sincerely

Lisa Summerhill
Trainee Clinical Psychologist

APPENDIX N:

Extract from Lara's interview demonstrating stage 2 of the IPA analysis

Stage 2: Key words capturing contents of the text

| | |
|--|--|
| <p>Sometimes I went to the toilet and I/and, well sometimes I sleep walked and just went to the toilet and came back in</p> <p>Right</p> <p>But most of the time I actually weed in my bed</p> <p>Right</p> <p>Instead of upstairs in the toilet</p> <p>OK. OK. So when/when you had an accident t night, so when you were having the dream about water and then you'd wake up in a wet bed, what was that like. What would happen then?</p> <p>I'd feel, um, I'd look and I'd see that I'd wet the bed, so I would go to my mum. But sometimes she wouldn't wake up so I didn't know what to do</p> <p>And what was that like</p> <p>Well when you feel as though you don't know what to do you feel a little bit scared and</p> <p>Yeah</p> <p>Everything</p> <p>So what would you do then when you, when you couldn't wake mum and dad and when you were feeling scared? What happened then?</p> <p>I woke my sister up J.</p> <p>Right. J's the oldest?</p> <p>Yeah</p> <p>Yeah. And what would J do?</p> <p>She'll take me and clean my bed up</p> <p>Would she? OK. And was that a nice thing or was it embarrassing. What, what was that like when J was</p> <p>Both</p> <p>It was both</p> <p>Both</p> <p>Yeah. OK. Was there anything that helped you at night to stop having an accident?</p> <p>Well I said to my mum last night that I could have a potty every where so I didn't wee</p> <p>Umum</p> <p>And that my mum said that about three would be enough and then I said ninety three more</p> <p>Right. OK. So is/would you/are you still having accidents at night now?</p> <p>No not really</p> <p>Not really</p> <p>The odd one</p> <p>The odd one. And when you have the odd one at night now</p> <p>Yeah</p> <p>Um. What's that like for you now, now that you're a bit older, when you have an accident?</p> <p>Well sometimes I may I may be able to change my own bed and get</p> | <p>Control</p> <p>Fear</p> <p>Sibling support</p> <p>Solution to accidents</p> <p>Humour</p> <p>Independence</p> |
|--|--|

Stage 2: Initial list of abstract theme titles

Difficulties learning to use the potty
Errors made using the potty
Parental support during potty training
Milestone achievement comparison with sibling
Toilet training fun new experience
Perceived transition into adulthood
Social identity
Independence contributing to perceived transition into adulthood
Attunement with mother's needs
Less physical contact and interaction with mother
Fear on the toilet
Seeking parental support and safety
Catastrophising thoughts/Fantasy feeding fear
Lack of control over bowel
Lack of sensation
Shame
Embarrassment
Lack of control over bowel when asleep
Feeling dirty
Disturbed sleep
Permanent reminder of accident
Defending father's response to accident
Physical pain
Helpless
Distress
Panic
Confusion regarding sensation of accident
Pants facilitating normalisation
Blaming dreams for night time accidents
Identifying with younger sister's discomfort
Dream content themes of water
Sibling support
Possible solution to accidents
Humour
Self-care development
Confusion over bowel and bladder functioning
Avoidance of social situations where accidents could happen
Fear of being bullied
Worry about having accidents
Toilet training method
Lack of social awareness – expecting all people to have the same problems
Unrealistic expectations for all people
Guilt
Prolonged discomfort in bed
Dad associated with absence or pain when helping

Suggestions of toilet adaptation to compensate for child's size
Suggestion of cues to indicate about to be taken to the toilet
Aggression and lack of empathy doesn't work
GP could normalise problems and decrease feeling of isolation
Assumption that others have sensory integration and can communicate this to parents
Assumption that child can communicate need to use the toilet to parent
Being calm and practical help to clean up helps child
Would share experiences with others to help them
Awareness of others feelings of isolation
Offer help to others by instruction
Pants allow feelings of independence
Pants decrease social awareness of problems
Avoidance of negative reactions to accidents
Acceptance of others decreases shame

APPENDIX O: Table summarising where in Lara’s transcript each theme appears

| THEME | APPEARANCE IN TRANSCRIPT (LINE NUMBER) |
|--|---|
| Difficulties with toilet training process | |
| Dreaming of water | 251, 265, 267 |
| Lack of sensation | 157 |
| Lack of bowel control | 129, 131, 159 |
| Lack of bladder control | 245, 279, 285, 322, 328, 354, 439 |
| Confusion regarding accidents | 215, 326 |
| Toilet training techniques | |
| Fun | 493 |
| GP normalising problems | 522, 570, 578, 586 |
| Being calm | 559 |
| Awareness of others feelings of isolation | 526, 581 |
| Toilet training method used by parents | 394 |
| Practical support | 306, 479, 561 |
| Family support | 14, 108, 202, 294, 298, 452, 663 |
| Comfort | 431 |
| Aggression and lack of empathy | 502 |
| Personal Consequences | |
| Independence/perceived transition into adulthood | 69, 240, 319, 602, 614 |
| Fantasy of what could happen on the toilet | 113 |
| Reminder of accident (stains and damp patches) | 166, 450 |
| Physical pain | 170, 184, 247, 627 |
| Less physical contact/interaction with mother | 78, 87, 89, 94, 436 |
| Social Consequences | |
| Fear of being bullied | 374 |
| Worry about having accidents/other’s response to an accident | 343, 347, 382, 648 |
| Need for acceptance | 196, 411, 423 |
| Social identity | 45 |
| Sibling comparison | 31 |
| Emotional Consequences | |
| Humour | 306 |
| Fun | 40 |
| Shame | 149, 163, 170, 370, 414, 653 |
| Embarrassment | 193, 368, 375 |
| Helplessness | 110, 288, 343, 374 |
| Distress | 188 |
| Panic | 213 |

APPENDIX P:

Detailed account of all dreams

2.2.2005

Being chased

Out in the pub with K (middle sister). Pub has different levels and sections. Everything is brown and dark with low lights. A man walks into the pub who I don't know but who I have just started to go out with. He is wearing a black jacket and jeans. He orders a drink and then he goes to sit down. K and I continue talking at the bar. The man then comes back and we all start to drink a shot of tequila. I don't drink mine. K continues to pull faces whilst she drinks hers. My boyfriend drinks his in one go.

I walk outside for some fresh air and the dream changes. It is spring outside - very light and the atmosphere is lighter. I am in a green field and the grass has dew on it. I have nothing on my feet as I walk on the grass. I think that there could be dog's muck on it so I start to hover above it and I skim the top of the long grass as I move across it. I pass a cream coloured hammock attached to a tree. It has a white cushion on it and I think about stopping to sit on it. But I continue through the field because I don't want my boyfriend to find me, even though deep down inside I want him to look for me. He does come outside and talks to me. He is gentle but then he becomes aggressive. I am not scared.

Dream changes and I am at a station. It is grey. An underground cream coloured train pulls up into the station and I get into it. When the train has left the station I feel a tap on my left shoulder. I turn around to see my boyfriend who looks like an ex-boyfriend of mine (BB), but he has dark hair instead of blonde hair. I feel disappointed but we go and find a seat to sit together. The seats are blue and mostly covered with other people's coats. We pass two little boys on the right who have two seats with their coats on whilst they are sat on two other seats opposite where their parents are sitting. I feel angry but keep walking without saying anything. We see two old seats in the doorway that we pull down to sit on.

8.2.2005

Dream 1

Need for space

In a car park. It is dark. My car is white. I thought I was going home but instead I move my car to another space. Then on shop mobility scooter trying to adjust handles so I am not slumped over. Tell people I am going for a ride but I will be back. There is a sense of danger. It is still dark. I then come back and go up to my big open plan bedroom. It is orange inside from the light. I start to tidy up when I hear J my housemate and her mum talking downstairs to K. I realise that J's stuff is in my room everywhere and I start to put it into a make-up bag

next to her single mattress on the floor. She walks into the room saying, “you didn’t have to do that.”

Dream 2

Acceptance of change and disruption

I am in a big garden. My friend S visits me and tries to hurt me. I am screaming for my family who eventually rescues me. Then S starts stalking me. He then turns into an old man. This time there are two male friends with me and we play a game for this man. He thinks that we are doing this because we want to but it is an attempt to get away. There are three concrete grey slabs from this world to the next. For the game we have to skateboard across the top slab without the two supporting slabs falling down. We skateboard across into the top floor of a house where there are hundreds of uneaten rotting meals in a dining room. We walk into the kitchen where there are lots of cats. There are huge slices of ham that we put onto plates. A big cat then snatches some meat from the pile.

So the man doesn’t come across knowing that we have succeeded we go back across. At this point the slabs fall down. We then end up back in this other world. The man tells us that it is “under the sea world”. We are on a seabed. There are purple skies and there is moss everywhere on the rocks around me. I feel amazed as I walk further into this world. As I do the rock that I am leaning against starts to move. We all run back towards the exit of this world. The slabs are now under the ground. The man says that we can just pull it out because it is under the sea and the ground is soft. An earthquake is starting. We get back to our world and realise that “under the sea world” is going to come into our world. Someone runs up the road and starts painting the steps yellow and white but it doesn’t work. I tell everyone that it is because there are different magnetic energies in the two worlds, which is causing the disturbance. We block up the energy coming through the door and we all know that it happened because we left the door open for too long. The dream then switches to after the earthquake has passed. I am sat by a fountain wondering what to do to put things right. An ornamental monkey grows bigger and comes to life. A baby monkey appears next to it. This baby monkey drops its hand into the water trying to catch a metal fish. This fish is made of bronze and is an aqua colour. The monkey misses and gives up and walks away. I tell everyone that this is what we should be doing, just accepting things as they are instead of fighting them.

16.2.2005

A new start

I am shopping, with a child in a pushchair. The child is a little boy with blonde hair. The shopping area looks like a fake set on a film. We go down some steps and at the bottom I check that the child is strapped into the pushchair as he is leaning forward and I am worried about him banging his head. There is a man with me who I am sure is S (boyfriend) but there is something that isn’t quite the

same about him. I can't see him very well. I tell S to leave us so we can do a few things. I then walk into a teashop with the pushchair.

At this point the dream changes and I am in a big house with lots of children, all of which are adopted. The house is actually alive itself and the children keep disappearing within the house. There is an incident in the bathroom where the bath tries to eat the baby. I can't get hold of the baby. It is upside down and drowning. I am about to grab hold of it's hair to pull it out but I don't need to because at that point I manage to get hold of it so I am relieved that I haven't had to physically hurt it whilst trying to rescue it. I then tell everyone to pack after talking to the house about leaving. It responds by opening and closing the curtains. I am the oldest male child and myself at the same time. The man of the house is packing but the wife who is now not me is refusing to pack. I am just throwing everything into a suitcase. A helicopter then arrives to take us away to our new house.

24.2.2005

Chaos/Fear of madness

I am on holiday somewhere with J (best friend from high school). We go into a tearoom and shop in one. I talk to a mother about a problem that she is having with her daughter swallowing her dummy. The mother demonstrates to me how this happens. The child then shows me the new bottle she has of which she cannot put the teat into her mouth but instead she has to lick it. I ask what she would do if she was thirsty. She said that she wouldn't get thirsty because she is licking the bottle all night. The bottle is full of blackcurrant fruitini. I decide to go and buy some for myself. I am standing at the counter and decide to buy two loaves of bread from a basket that is in front of the counter. J then tries to encourage me to buy a red windmill on a stick. I hand it back to the female shop assistant with long blonde hair saying to her that I am trying to save some money for my trip to Amsterdam. Then J orders some coloured fudge. As she does so I start looking at the chocolate. For some reason I then decide to buy two fish. A man (who is the man that I used to see when I was a child) appears and starts to get a fish out of the tank. It is brown and has pointy sharp fins. He puts it in a bag with no water in it. I say this and he then fills it up and puts a clip on the top. I then get anxious suggesting that the fish might die on the plane back home. The man says, "it will not die". I query when I need to put a hole in the bag to let oxygen in. The man says, "it isn't a plastic bag." He walks away and I follow him. As I do this a big blue box is rushed in by a group of people all shouting and panicking. The man steps backwards and presses the fish against my chest. I move away and check the fish and myself. The fish wriggles then attaches itself to behind my right knee. I try to pull it off but I can't and there is blood appearing on my leg. I walk towards this man who is now looking at another males head in the blue box. Someone shouts that a shark has bitten this man. The man in the box is talking to the other man. I realise then that he has a body and the bite is on his neck. I then walk away from the room that the box is in. I am suddenly in a fish market with stalls with black frames. I try to free my fish and the man who sold it is there behind me saying that if I sell the fish or set

it free it will be caught again and sold back to me. The fish is in the bag again at this point. I try running away from this man who is being aggressive.

I am now getting off a train and walking out of the station. I am somewhere back in England but I don't know where. Time changes to the future and I carry on walking. The man walks past me looking slightly neater than he did abroad but he has hospital bands on his wrists and white plasters on the ends of his fingers. I realise now that he is psychotic.

24.03.2005

Rescuer

I am flying around with a female friend. I can't quite see who it is. The dream is grey and dark. We settle down where there is a car with lots of cats locked inside it. The car is in a large carport. We break into the car to sit and stroke the cats. We then decide to set them free. As the last few cats are crawling out of the back window of the car we start to follow them as we see the owner of the car approaching. I am still trying to crawl out of the car when the man approaches me. He doesn't seem as angry as I thought he would be, but I don't delay in getting away as quickly as possible. My friend disappears from the dream at this point and the dream then changes.

There is a man who I know is trying to kill people and I keep having a conversation with him then I fly away before he has any reason to kill me. However, I can't fly as high or as fast as I would like to be flying. I have to squeeze through a tight window to fly away. I always do this in a hurry before the man comes and pushes me out, a result of which I fear would be that I would injure myself by not being able to fly high enough in time.

I am then in a session with one of the children that I saw on my core child placement. This is his last session and he suggests that he is being hurt, although he doesn't explicitly say that he is. I inform my supervisor and ask her to accompany me to the child's house with my manager to question the mother about the father when he is not there and without revealing to her what has been revealed by the child. We are then sat in the boy's home and whilst the mother is being interviewed I am sat next to the boy looking at him. At one point he becomes distressed and clings to me. His mother does not seem distressed by this. I want to take the boy home with me but instead I explain to him why I cannot do this even though this is also his wish.

Dream then switches to me witnessing the serial killer trying to kill people at a Baroque style masquerade ball. I wake up.

26.3.2005

Fear of rejection

I am having an argument with H (trainee friend) about the way in which something is done in our research. I walk out very angry and do not wish to talk to anyone. I am then sat in a school canteen eating a sandwich. Sa (trainee friend) approaches me and I ask her to leave me alone. She starts to try to advise me and I say I am not interested and I tell her that I have fallen out with other people that day so losing another friend is not going to bother me. At this point she says that we are no longer friends. I then get up and walk away. I pass Sh (trainee friend) and explain to her what has happened saying that I am not bothered about having lost my friends although inside I am feeling really upset. I explain to Sh that I wish that people could understand me and see how much I struggle.

Self-preservation

I am walking in a busy street. It is nighttime so I can see all of the traffic headlights in the road. The traffic is busy. All of a sudden a lorry rolls onto one side. This happens with another lorry and a bus. I am watching to see if any cars will crash into these vehicles. As I am watching, the second lorry that rolled over is sliding down the road towards me. I start to run away from it so that I will not be crushed. As I run away I think that I have not stopped to help the lorry driver, as has another person with the original lorry that rolled over. I decide to keep running even though I feel guilty.

Assertiveness

I am on a forensic placement. I am not happy there and am aware that I am struggling to work with some of the clients because I am scared of them. At lunch one day I ask my supervisor if I can speak to her after lunch about placement related issues. When I am in her office she says that she is glad that I have asked to see her because she wanted to talk to me about my progress on placement. She then proceeds to criticise every aspect of my work. She identifies that I am avoiding seeing clients and that I have no respect for risk issues, given that she witnessed me forgetting to lock a door behind me after leaving one of the forensic wards. We are then in a long brown corridor continuing this conversation. There are white doors along this corridor. At this point my supervisor informs me that things will need to radically change for me to pass my placement. I defend myself by saying that I have not been shown how to work the security doors and other systems and that I have not had the chance to develop my confidence of working with these people because I have not been able to see my supervisor as often as I would have liked to. I walk away after the conversation feeling proud of myself for having defended myself. However, I dread going back into work the next day. I decide to go to the hairdressers to pamper myself. After having a haircut I ask to have a head

massage. As I bend over for the hairdresser to massage my head I can see myself from her perspective. I have dandruff flakes appearing, which I do not like so I stop seeing things from her perspective. After she has run the wooden massager over my head once she stops to work on a young man who has just walked into the salon. I refuse to pay for my massage and leave with a wet head.

As I leave the salon it is then the next day and I am on my way to work. It is raining so I go inside a shop (British Homes Stores) to take cover. I am contemplating not going into work and instead phoning in sick and spending the whole week at home. I start looking at some dresses but fear that I will be caught delaying my arrival at work. I decide then that I will go into work. I then walk through the homeware section where there are brown and beige coloured voile panels that I stop to look at for redecorating the bedroom at home. I then stop to look at the bedding and a male shop assistant that has a learning disability says, “excuse me” as he reaches in front of me to take something off the shelf. As he does this he places his hand on my lower back underneath my top. I tell him to stop and he seems surprised and reacts as though there was nothing wrong with what I had just done. As I walk away to go up some stairs towards the exit I wonder if there is something wrong with my judgement of people. I admit to myself that I have a problem with being touched by people. I make a decision then to try and overcome my fear of working with people in the forensic setting. I walk through the shop exit and am immediately at the bottom of a flight of stairs up to the entrance to work. It is all grey concrete with a red door and handrail. Lots of colleagues are climbing these stairs and I join them. My supervisor is then behind me watching me. Some people are going through the red door whilst someone opens the whole left hand side wall, which is now red, and hops over the banister through another exit, which is faster. I approach this exit first and no-one else wants to use it after me so I realise that I have to make sure that the door is then locked afterwards. As I am about to pull the banister into place my supervisor says my name in a tone suggesting that she is reminding me to do it. I am angry that she has made a scene in front of my work colleagues. I then plan what I am going to say to her when I reach her office; “it is not acceptable for you to humiliate me like that in front of my colleagues, I only need telling to do something once and then I adjust accordingly”.

07.04.2005

Feeling small and vulnerable

I am walking down a street with a group of friends but I can't quite determine who they are, although I know that they are friends of both genders. As we walk down the road, I realise that it is nighttime and we need to sleep somewhere. We do not know the street that we are in but I know that it feels like a different time (something like the seventies). We knock on someone's door and ask if we can come in. A man in his fifties answers the door and lets us in without hesitation. He goes to make us all a cup of tea. As he does this there is a knock at the front door. I answer the door and another man of a similar age but a smaller build

looks shocked when I open the door. He asks to see the person that answered the door to us. This man comes to the door and lets the second man in. We all then realise that these men are criminals and are robbing this house as well as using it as a base to hide after they have attacked people. At the first opportunity my friends and myself leave the house.

The dream changes and I am with K (my middle sister) shopping for some sweets in a pound shop. The shop is about to close so we have to hurry up. When we leave we decide to walk home. At one point in the dream I am in a lift with K. This lift is half of a whole building that is moving and at certain times when in the lift it moves faster and slower as it is going up and down. I stay in this lift for a while with people coming and going. I then decide to get out of this lift and it opens the door onto a concrete jetty at a port. At this point K has disappeared and I realise that I am here to play in the water with my friends. After playing with them for a while I get out of the water and get dressed although this happens without my dreaming it. I am then asked by my cousin R who has appeared in the water to swap the lilos that we have got. I think that I can do it without getting wet so I go out on the water on my lilo. When we go to swap over she deliberately pulls the lilo and I end up in the water. I then start to hover above the water but cannot get very high. I start to panic because I can see two large shadows, which I think are whales, below me in the water. I want to get back to dry land quick but cannot. Just before I wake up I realise that these two objects are bombs.

Exploding head

I am sat in a female friend's house (although this is a woman in her forties and I am that age and I have not met her in real life). We are in the dining area attached to the kitchen. Three leopard cubs walk past the window and I see them and say, "Is that tiger cubs?" As I say this they walk into the dining area past my legs. One stops and rubs itself against my legs. As it does so I realise how dirty they are and say to my friend that I am not going to touch them until they are clean. The dream then switches to them being clean, but there is only one in the room, which is wet. I ask my friend where the other cubs are and she says that she is drying them. I panic and look in the tumble drier to see them in with the sheets being tumble-dried. I quickly open the door and explain to my friend why they should not be put into a tumble drier. I am afraid that they will die. I then realise that my friend has also put bronze cases around them to help them dry quicker. I cannot get the cubs out of these and decide to cut them out with secateurs.

I am then walking with K. As I do I realise that I live with her in my ex-boyfriend's (C) father's house, although they do not know that we live there because we live in what used to be the servants quarters. We walk all around the grounds and can see that the dining area is set for a large meal. I realise that my boyfriend lives in this house with his ex-girlfriend (L) as well as with his father. As we walk around I realise that we have a secret passage to get into the house so that no one will notice us. As we enter the main doorway and then go through a door in the staircase I realise that it is a very small space that we have to climb

up, to reach where we live. As we walk through a white wooden corridor a middle aged woman with dark hair walks past us. She is a servant in the house and she seems to know us because she says, “hi” as she passes us to go through another corridor to get to the next floor. K and I continue on our path as it gets narrower. We then have to climb up some white wooden stairs in a very thin corridor. I realise that I am not going to get my head through the opening into the doorway where there will be space and I realise that I cannot breath. My head feels a lot bigger than my body and I think that if I could just get my head through this space then I will be able to breath again. I decide to rip the wood to create some more space. As I attempt this K tells me not to because I will not be able to manage it. Instead I try moving my head in different positions, which doesn’t work so I rip the wood. As I am doing this I see the servant that passed us in the corridor go through the door in front of us. I wonder to myself why K and I didn’t take the easier route like the servant did.